

**DEPARTMENT OF DEVELOPMENTAL SERVICES**

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DATE: October 19, 2004

TO: INTERESTED PARTIES

SUBJECT: STUDY OF DEATHS THAT OCCURRED IN 1994

Enclosed for your information is "Causes and Contributing Factors: Mortality of Individuals with Developmental Disabilities" (1994 Cohort Study). This report was produced by California State University, Sacramento (CSUS) Division of Nursing, in collaboration with the Department of Developmental Services (DDS) and regional center staff. The study was initiated in 1999 and completed in 2002.

The 1994 Cohort Study focused on deaths of consumers served by the regional centers. This study was designed to examine factors related to mortality and morbidity, including personal characteristics and the nature of health care/supervision provided in out-of-home settings, including Community Care Facilities (CCF) and Developmental Centers (DC).

There were two main findings in the 1994 Cohort Study. The first was that the quality of health care, including supervision and treatment, continued to be an issue for some individuals who reside in out-of-home settings. The second finding was that the regional center often did not have complete documentation in regards to individuals' medical records.

There were several drawbacks in completing this study. Medical experts in the 1994 Cohort Study were geographically diverse and unable to meet as a group. This prevented group discussion, which impeded agreement amongst the clinicians and therefore, problem resolution was difficult to achieve. Also, the medical experts were not clinicians from the regional centers and did not have a comprehensive understanding of the regional center system. For these reasons, DDS commissioned a new study (referred to as the 1999 Cohort Study) to pursue additional questions on the quality of care for consumers living in community settings.

The study did not have access to the individual's medical record and relied on the information in the regional center record, the residential file and any other information made available.

**"Building Partnerships, Supporting Choices"**

Recommendations made in the 1994 Cohort Study included the following:

- Support efforts to promote preventive health care.
- Continue DDS's efforts to educate physicians and other health care professionals on caring for individuals with developmental disabilities.
- Intensify oversight and client-specific training for residential facilities.
- Provide training to regional center staff on:
  - Identifying appropriate responses to health status changes, such as contacting a supervisor or a physician;
  - Documenting and monitoring consumer health needs and safety; and
  - Developing and implementing the use of care plans.
- Provide multidisciplinary teams to assess and monitor consumers with multiple, chronic health problems.
- Ensure the regional centers have effective mechanisms for identifying consumers who have health care needs requiring close monitoring or supervision, and bringing these consumers to the attention of clinical team members for appropriate intervention and follow-up.

In response to these and other recommendations, DDS has taken the following actions:

- Contracted with an Independent Risk Management Contractor. One major activity of the contractor is to complete bi-annual mortality reviews for consumers living in the community.
- Implemented the Electronic Special Incident Reporting (SIR) System.
- Funded Clinical Teams at regional centers to assist in addressing the complex and inter-related health problems of individuals with developmental disabilities, and to promote preventative healthcare measures such as screening exams and vaccinations.

## Interested Parties

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- Implemented the Health Status Review, which reviews the physical, mental, and oral health status of each consumer at their annual Individual Program Plan meeting.
- Conducted the Longitudinal Study (tracking quality of life and health issues for every person moving from a developmental center into the community) that is now required by law to be done every year.
- Developed a monthly web article and quarterly newsletter ([www.ddssafety.net](http://www.ddssafety.net)) that is distributed both electronically and by hard copy. The newsletter has concentrated on the following topics:
  - Heart Health;
  - Emergencies;
  - Summer Safety;
  - Falls;
  - Mealtime Safety;
  - Physical Management;
  - Medications;
  - Nutrition and Diet; and
  - Aging.

The monthly web article, which is distributed electronically, has concentrated on the following topics:

- Respiratory Health;
- Medication Safety;
- Illness and Injury;
- Risk Management;
- Personal Safety;
- Victimization; and
- Obesity.

The web articles are written for:

- Consumers and Families;
- Service Providers;
- Clinical Professionals; and
- Regional Center Staff.

Interested Parties

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- Continued Healthcare Professional trainings for medical providers in the community. To date, 34 trainings have been conducted with approximately 3,500 healthcare professionals trained in the complexities of the care and treatment of persons with developmental disabilities.
- Continued publication of the *Wellness Digest*, which provides information on specific health issues.
- Developed an on-line resource ([www.ddhealthinfo.org](http://www.ddhealthinfo.org)) for physicians, providers and families, regarding developmental disabilities and services available through the regional center system (1998).
- Established a plan for developing "Best Practice Guidelines" for regional centers to improve the accuracy and completeness of regional center medical records.

DDS continues to pursue improvements as recommended not only by this study, but as a result of many reports and recommendations from numerous sources as well as DDS's own analyses. Strong emphasis is currently focused on health promotion, early identification of conditions, and increased quality management and accountability systems of health outcomes. In addition, we continue to support the Wellness Initiative and collaborative partnerships to promote quality health care services for all Californians with developmental disabilities.

Please contact Jo Ellen Fletcher, Chief of DDS's Health and Wellness Section, at (916) 654-2133 if you have any questions regarding this study.

Cordially,

**Original Signed by**  
CLIFF ALLENBY  
Director

Enclosure

**Causes and Contributing Factors:**  
**Mortality of Individuals with Developmental Disabilities**  
**1994**

NOTE: Some information directly related to a specific consumer(s) was deleted to ensure confidentiality pursuant to Welfare and Institutions Code section 4514.

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We would like to extend a special thanks to staff at the California Department of Developmental Services. In particular, we thank Roberta A. Marlowe, Ph.D., for insisting that we look "at it all". Ron Huff, Ph.D., for his support and guidance. Carrie Theis and Jim White for their assistance with data and insight. Judith Angell for her help in correctly identifying client status.

Two experts on the health of individuals with developmental disabilities provided us with outstanding insight, support and guidance, Mary Lu Hickman, M.D., and Mary Van Loon, RN, MSN. In addition to bringing a great deal of wisdom to the topic, Mary Van Loon also donated numerous hours to help develop the abstraction instrument and to assist with coding experts' written comments.

This study could not have been done without the help of many CSUS nursing graduates. Hitachi Industries generously donated 10 laptop computers that enhanced our ability to gather data quickly and accurately. We continue to use these wonderful computers on ongoing studies.

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## **PURPOSE OF THE STUDY**

In response to conflicting research findings and increasing concern over the quality of health care for persons with disabilities living in the community, the California Department of Developmental Services commissioned California State University, Sacramento Division of Nursing to conduct this study. Mortality factors and quality of on-going residential health care among persons with developmental disabilities who resided in out-of-home settings were examined. Data sources included the Client Development Evaluation Report (CDER) data, and Bureau of Vital Statistics records on death. In addition, this study gathered in-depth data from client facility records for a random sample of those persons served by DDS in 1994 who resided in out-of-home settings at the time of death. The study was designed to examine factors related to mortality and morbidity, including person characteristics and the nature of health care/supervision provided in out-of-home settings.

## **BACKGROUND**

Social reform in the field of developmental disabilities has resulted in de-institutionalization and the placement of individuals with developmental disabilities in the least restrictive environment possible. Studies have shown that the quality of life is better for individuals with developmental disabilities who reside in community settings as opposed to large state institutions (Stancliffe & Lakin, 1998; Walsh & Kastner, 1999).

The merits and liability of the trend to normalize the living environments of individuals with developmental disabilities is the source of controversy among those associated with this population (Landesman & Butterfield, 1987). A primary concern is that health care systems that recognize the special needs of individuals with developmental disabilities may not be in place in community settings. Kastner, et al., (1993) point out, "Although residence in the community should not affect mortality, access to services may have an impact. In particular, the quality and accessibility of health care services and their coordination with other human services provided in the community may have a significant effect on mortality" (p. 286).

Research focusing on the unique health needs of this population has consistently shown that factors associated with increased risk of mortality are profound retardation, decreased mobility, need for a nasogastric tube or gastrostomy tube feedings, a lack of toilet skills, and the

presence of a seizure disorder (Cole, et al., 1994; Eyman, et al., 1988; Eyman, et al., 1986; Eyman, et al., 1990; Eyman, et al., 1993). The most frequent cause of death for individuals with these types of disabilities has been found to be respiratory diseases, such as pneumonia (O'Brien, et al., 1991). Heart disease and cancer are more frequent causes of death among higher functioning individuals with developmental disabilities (O'Brien, et al., 1991). The ability of existing health care systems to provide the types of supports needed by this population has been questioned. Community-based physicians may not have the experience and skill to provide the full range of services needed by individuals with developmental disabilities because of their complex health needs (Eyman, et al., 1990; Strauss & Kastner, 1996; Zirig, 1987; Zirig, et al., 1988).

Studies on risk of mortality by type of setting have resulted in conflicting findings. Strauss found the risk of mortality much higher among individuals residing in community settings compared to those living in state developmental centers (Strauss, et al., 1996; Strauss & Kastner, 1996). Others have found no difference in rates of risk (O'Brien & Zaharaia, 1998). Although valuable, these studies do not provide data on the aspects of care and services that contribute to mortality risks—they can only address association and cannot address causation. They rely on evidence that is indirect, using primarily CDER data, and depend heavily on statistical models designed for each individual's inherent risk of death. If indeed, people are more likely to die in one type of setting versus another what is it about those settings and the health care delivery system that makes a difference?

## **STUDY DESIGN AND METHODS**

This study focused on exploring the influence of health-related services on the mortality of a randomly selected sample of individuals who died in 1994. Underlying issues that contribute to mortality among individuals with developmental disabilities were addressed. Previous studies noted differences in mortality based on the type of residential facility. This study was designed to examine the differences in documented care by type of residential facility. A random sample of all of those who died while residing in out-of-home settings was drawn. Extensive data were gathered on the delivery of health-related services for the sample, and findings were reviewed and rated by a panel of experts in the field of developmental disabilities (see page 13 for more detail). Based on the review by expert panelists, the qualitative differences in care were identified by type of residential setting.

### **Research Questions**

1. Did the quality of health care or supervision by physicians or residential staffs contribute to mortality of individuals studied?
2. Were there differences in the quality of health care or supervision provided to individuals with developmental disabilities by physicians or residential facility staff based on the type of residential setting?
3. Did the consumer's or family member's wishes contribute to mortality?
4. Did Advanced Care Directives play a role in preventable mortality?

A random sample of individuals who had resided in community based out-of-home settings was selected for inclusion in the study. The sample was stratified to include 50% of those residing in each category of community-based residential setting. To ensure an adequate number of DC clients to enable a comparison of this group to all others residing in out-of-home settings, 100% of those who had resided in DC's were included in the study.

Data available in DDS files were supplemented with detailed information on the sample. These data consisted of Bureau of Vital Statistics for death certificates, Special Incident Reports about the situation surrounding the death, and data specially collected for this study from regional center and residential facility records. This permitted focused statistical analyses that rely less heavily than previous studies on accurate control of inherent risk of death, as well as

cause-specific analyses and exploration of what relevant factors are different between institutional and community residential settings.

The study plan follows:

1. Data collection instruments were developed and piloted. These focused on the following areas:
  - General preventive health care
  - Preventive health care relevant to the cause of death, including screenings and medication management, as applicable
  - History of access to urgent and specialty care, and any barriers to access encountered
  - Ongoing medical care
  - Emergency response before the death
  - Consumer and family wishes and compliance concerning health care, including Advanced Care Directives
  - Residential supervision and care usually provided to the consumer
  - Consumer and family wishes and compliance concerning supervision
  - Any other aspects of care that may have influenced the occurrence or timing of the death
2. Regional center and residential facility records were reviewed and data were collected. Registered nurses with special training and experience working with individuals with developmental disabilities abstracted data using standardized forms. Inter-rater reliability was established at 85% or greater. Ten per cent of all records were audited to ensure validity.
3. An expert panel reviewed the data on each death to categorize the death in several ways (see Appendix C1 for a copy of the Expert Panel Form). The panel consisted of nationally recognized physicians and nurses who specialize in the care of individuals with developmental disabilities. The data were reviewed to ensure that information would not enable the panel to ascertain whether the consumer resided in a community-based or state-run facility. Panelists decided the following:
  - A. Cause of death.

- B. An overall assessment of whether better medical and residential health care might have prevented the death
  - C. Specific aspects of health care that might have prevented the death:
    - Better preventive health care
    - Better medical management of the underlying condition
    - Better emergency response near the time of death
    - Better residential care management of consumer's health
  - D. The quality of health care:
    - Preventive health care
    - Medical management of the ongoing health problems
    - Residential care management of consumer's health
4. All available data from computerized databases, field data collection, and the expert panel reviews were analyzed statistically. This included both descriptive and comparative analyses.
5. Results of all statistical analyses were reviewed and discussed. Experts in the fields of medicine, nursing, and statistics worked together to glean the maximum possible insight from the data collected. One or more publications will be prepared describing the methods, results, and interpretations of this study, along with possible areas where further research would be most valuable.

### **Statistical Methods**

Four expert panelists rated the quality of health care of each client record. The ratings addressed Special Care Directives, Emergency Response, Services Provided by Physicians, Services Provided by Residential Care Providers, and Health Care Systems (see Appendix C1 for detail of factors rated). These quality of care ratings were analyzed as ordered responses, with the “best” rating being that panelists agreed (at least three of the four) that quality was acceptable, the “worst” rating being that panelists agreed that quality was poor, and failure to reach agreement counted as intermediate between best and worst. When panelists rated quality as "Not Applicable" or "Unable to Determine," the quality rating was set to missing and excluded from tabulations and analyses.

A composite overall variable was defined as the worst rating on three items that asked whether the death might have been prevented by better quality in the following specific areas: preventive care, residential care, or health care delivery including both medical and residential aspects. If panelists agreed that changes in any of these areas could have prevented death, the individual's death was rated as preventable.

Statistical analyses utilized the Mann-Whitney test to obtain p-values for comparing quality ratings at different residential settings. These summarize the strength of evidence against differences in quality ratings being explainable as random flukes. The Mann-Whitney test depends only on the ordering of the ratings and does not assume that they follow a normal distribution or that "No Agreement" lies exactly half way between the best and worst ratings.

Analyses of the adult group used a combination of population-wide data and data from the expert panels' evaluations of sampled deaths. One analysis modeled risk of death while excluding those cases where panelists agreed that poor quality of care did not contribute to the death. This used the overall quality rating (described above) and was designed to focus more directly on the role of quality of care. Another analysis modeled risk of death while excluding deaths that may have been influenced by choices made by clients or their family members. These excluded deaths where clients had special care directives or whose deaths may have been contributed to by refusal to comply with medical care, lifestyle choices, the client's own actions, or family choices regarding medical management, hospitalization, or treatment. For both analyses sample-weighted logistic regression models were calculated using the *svylogit* function in the Stata statistical package (Stata Corporation, College Station, Texas). Because no deaths were sampled from clients who had been living at home, no evaluation of this residential setting was possible in these analyses.

### **Sample Selection & Description**

California Department of Developmental Services provided a listing of all persons within their system known to have died in 1994. Of the 1,168 people identified, 640 lived with their families or independently and were excluded from the study, since the focus was on those living in out-of-home settings. Demographic characteristics of all who died in 1994 are displayed in Table 1. Since this study focused on those individuals living in out-of-home settings, the sample selected is proportionately older than those not selected. There were no statistically significant

**Table 1**  
**Age, Gender, and Race/Ethnicity of Total Deaths by Sample Selection and Placement**

Age, Gender, and Race/Ethnicity of Total Deaths by Sample Selection and Placement										
	Out-of-Home						Home		Other	
	In Sample		Not in Sample		Total					
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Age Group										
<11	40	11.6	24	13.1	64	12.1	340	55.7	22	75.9
11-20	30	8.7	16	8.7	46	8.7	80	13.1	2	6.9
21-30	46	13.3	18	9.8	64	12.1	61	10.0	1	3.4
31-50	107	31.0	47	25.7	154	29.2	96	15.7	3	10.3
51-70	77	22.3	54	29.5	131	24.8	28	4.6	0	-
>70	43	12.5	24	13.1	67	12.7	6	1.0	1	3.4
Unknown	2	0.6	0	-	2	0.4	0	-	0	-
Total	345	100.0	183	100.0	528	100.0	611	100.0	29	100.0
Gender										
Male	206	59.7	101	55.2	307	58.1	333	54.5	14	48.3
Female	138	40.0	82	44.8	220	41.7	264	43.2	14	48.3
Unknown	1	.3	0	-	1	0.2	14	2.3	1	3.4
Total	345	100.0	183	100.0	528	100.0	611	100.0	29	100.0
Race/Ethnicity										
Hispanic	55	15.9	23	12.6	78	14.8	154	25.2	5	17.2
White	241	69.9	133	72.7	374	70.8	251	41.1	9	31
Other	12	3.5	4	2.2	16	3.0	60	9.8	0	-
Unknown	5	1.4	3	1.6	8	1.5	52	8.5	9	31
Total	345	100	183	100	528	100.0	611	100	29	100

differences in demographic characteristics between those in the sample and consumers in out-of-home placement not in the sample.

Developmental characteristics of individuals who died are displayed in Table 2 on the following page. There were statistically significant differences in the distribution of three characteristics between consumers included in the sample compared to those not included. A higher percentage of consumers included in the sample had generalized seizures, profound retardation, and low self-care ability. This is probably due to the high proportion of Developmental Center clients.

**Table 2**  
**Developmental Characteristics of Total Deaths by Sample Selection and Placement**

	Out-of-Home						Home		Other	
	In Sample		Not in Sample		Total		Number	Percent	Number	Percent
	Number	Percent	Number	Percent	Number	Percent				
Cerebral Palsy										
No	184	53.3	115	62.8	299	56.6	258	42.2	2	6.9
Yes	147	42.6	60	32.8	207	39.2	189	30.9	0	-
Unknown	14	4.1	8	4.4	22	4.2	164	26.8	27	93.1
Total	345	100.0	183	100.0	528	100.0	611	99.9	29	100.0
*Seizures										
None	167	48.4	103	56.3	270	51.1	244	39.9	2	6.9
Partial	12	3.5	10	5.5	22	4.2	33	5.4	0	-
Generalized	98	28.4	24	13.1	122	23.1	98	16.0	0	-
Other	54	15.7	38	20.8	92	17.4	69	11.3	0	-
Unknown	14	4.1	8	4.4	22	4.2	167	27.3	27	93.1
Total	345	100.0	183	100.0	528	100.0	611	99.9	29	100.0
*Mental Retardation										
None	10	2.9	8	4.4	18	100.0	89	14.6	0	-
Mild	57	16.5	33	18.0	90	17.0	83	13.6	0	-
Moderate	48	13.9	33	18.0	81	15.3	72	11.8	0	-
Severe	58	16.8	42	23.0	100	18.9	59	9.7	0	-
Profound	142	41.2	50	27.3	192	36.4	58	9.5	0	-
Unspecified	16	4.6	9	4.9	25	4.7	86	14.1	2	6.9
Unknown	14	4.1	8	4.4	22	4.2	164	26.8	27	93.1
Total	345	100.0	183	100.0	528	100.0	611	99.9	29	100.0
Ambulation										
Yes	123	35.7	76	41.5	199	37.7	155	25.4	0	-
No	204	59.1	93	50.8	297	56.3	273	44.7	1	3.4
Unknown	18	5.2	14	7.7	32	6.1	183	30.0	28	96.6
Total	345	100.0	183	100.0	528	100.0	611	99.9	29	100.0
*Self-care Ability Levels										
0-25 (low)	152	44.1	54	29.5	206	39.0	218	35.7	2	6.9
26-50	44	12.8	30	16.4	74	14.0	52	8.5	0	-
51-75	52	15.1	44	24.0	96	18.2	41	6.7	0	-
76-100 (high)	83	24.1	47	25.7	130	24.6	136	22.3	0	-
Unknown	14	4.1	8	4.4	22	4.2	164	26.8	27	93.1
Total	345	100.0	183	100.0	528	100.0	611	99.9	29	100.0
Developmental Levels										
0-25 (low)	162	47.0	68	37.2	230	43.6	219	35.8	2	6.9
26-50	80	23.2	50	27.3	130	24.6	62	10.1	0	-
51-75	56	16.2	39	21.3	95	18.0	77	12.6	0	-
76-100 (high)	33	9.6	18	9.8	51	9.7	89	14.6	0	-
Unknown	14	4.1	8	4.4	22	4.2	164	26.8	27	93.1
Total	345	100.0	183	100.0	528	100.0	611	99.9	29	100.0

\*  $\chi^2$   $p \leq .05$



One hundred and twenty-three resided in California Developmental Centers (DCs), and 369 lived in community based out-of-home settings, such as Skilled Nursing Facilities (SNFs), Intermediate Care Facilities (ICFs), and Community Care Facilities (CCFs) (see Table 3).

<b>Table 3</b> <b>Death In 1994 For Those In Out-Of-Home Placements (N=528) By Type Of Residence</b>						
<b>Residence</b>	<b>Not in sample</b>		<b>In sample</b>		<b>Total</b>	
	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>
Acute/general hospital	10	5.5	14	4.1	24	4.5
Developmental Center	1	0.5	122	35.4	123	23.3
CCF	94	51.4	99	28.7	193	36.6
ICF	31	16.9	41	11.9	72	13.6
SNF	46	25.1	68	19.7	114	21.6
Other	1	0.5	1	0.3	2	0.4
Total	183	100.0	344	100.0	528	100.0

Note: Distribution by living arrangement based on CDER data.

Because of the importance of comparisons between DCs and community settings and because so few individuals had resided in DCs, all of those residing in DCs were included in the study. For comparison, a fifty percent random sample of individuals who had resided in community based out-of-home settings was selected for inclusion in the study using a computerized random sample selection program. The sample was stratified by type of facility (SNF, ICF, CCF, Other) and category, such as ICF-DD, ICF-DDH (1-6 bed), to ensure proportionate representation of all settings. Thus, 50% of those in each type of strata were selected for inclusion in the study.

Demographic characteristics of the sample by type of residence selected for this study are displayed in Table 4. A higher proportion of older people resided in SNFs, while disproportionately younger individuals resided in ICFs and other community living arrangements.

**Table 4**  
**Age, Gender, and Race/Ethnicity of DDS Sample by Type of Residence**

	DC		SNF		ICF		CCF		Other CLA	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
<b>Age group</b>										
<1	1	0.9	0	-	0	-	2	2.6	4	28.6
1-10	8	7.5	5	5.9	4	9.1	5	6.6	9	64.3
11-20	7	6.5	2	2.4	10	22.7	8	10.5	0	-
21-30	17	15.9	11	12.9	11	25.0	6	7.9	0	-
31-50	45	42.1	16	18.8	13	29.5	27	35.5	1	7.1
51-70	18	16.8	29	34.1	6	13.6	18	23.7	0	-
>70	11	10.3	22	25.9	0	-	10	13.2	0	-
Total	107	100.0	85	100.0	44	99.9	76	100.0	14	100.0
<b>Gender</b>										
Male	72	67.3	48	56.5	28	63.6	38	50.0	8	57.1
Female	35	32.7	37	43.5	16	36.4	38	50.0	6	42.9
Total	107	100.0	85	100.0	44	100.0	76	100.0	14	100.0
<b>Race/Ethnicity</b>										
Asian	3	2.8	2	2.4	1	2.3	2	2.6	0	-
Black	4	3.7	3	3.5	4	9.1	6	7.9	2	14.3
Filipino	1	0.9	0	-	1	2.3	0	-	0	-
Native American	0	-	0	-	1	2.3	0	-	0	-
Hispanic	16	15.0	6	7.1	10	22.7	12	15.8	3	21.4
White	78	72.9	64	75.3	24	54.5	53	69.7	2	14.3
Other	2	1.9	2	2.4	1	2.3	1	1.3	0	-
Unknown	3	2.8	8	9.4	2	4.5	2	2.6	6	50.0
Total	107	100.0	85	100.1	44	100.0	76	99.9	14	100.0

Note: Distribution by living arrangements based data abstracted from client records, and excludes those clients for whom records were not available.

Developmental characteristics differed markedly by type of residence (see Table 5). The most medically vulnerable group lived in DCs: the majority had CP, seizure disorders, were non-ambulatory, profoundly mentally retarded, with no self-care abilities, and lower developmental levels. The lowest risk group resided in CCFs.

**Table 5**  
**Developmental Characteristics of DDS Sample by Type of Residence**

	DC		SNF		ICF		CCF		Other CLA	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
<b>Presence of Cerebral Palsy</b>										
No	26	24.3	60	70.6	21	47.7	60	78.9	3	21.4
Yes	80	74.8	19	22.4	22	50.0	14	18.4	4	28.6
Unknown	1	0.9	6	7.1	1	2.3	2	2.6	7	50.0
Total	107	100.0	85	100.1	44	100.0	76	99.9	14	100.0
<b>Seizures</b>										
None	32	32.7	52	61.2	13	29.5	49	64.5	5	35.7
Partial	6	5.6	2	2.4	1	2.3	2	2.6	0	-
Generalized	63	58.9	10	11.7	12	27.3	8	10.5	0	-
Other	2	1.9	15	17.6	17	38.6	15	19.7	2	14.3
Unknown	1	0.9	6	7.1	1	2.3	2	2.6	7	50.0
Total	107	100.0	85	100.0	44	100.0	76	99.9	14	100.0
<b>Mental Retardation Level</b>										
No Retardation	0	-	3	3.5	2	4.5	3	3.9	1	7.1
Mild	3	2.8	19	22.4	5	11.4	22	28.9	3	21.4
Moderate	6	5.6	20	23.5	4	9.1	15	19.7	0	0.0
Severe	13	12.1	10	11.8	11	25.0	20	26.3	1	7.1
Profound	83	77.6	25	29.4	17	38.6	10	13.2	0	0.0
Unspecified	1	0.9	2	2.4	4	9.1	4	5.3	2	14.3
Unknown	1	0.9	6	7.1	1	2.3	2	2.6	7	50.0
Total	107	100.0	85	100.0	44	100.0	76	99.9	14	100.0
<b>Ambulation</b>										
Yes	15	14.0	25	29.4	17	38.6	56	73.7	1	7.1
No	91	85.0	54	63.5	26	59.1	18	23.7	6	42.9
Unknown	1	0.9	6	7.1	1	2.3	2	2.6	7	50.0
Total	107	99.9	85	100.0	44	100.0	76	100.0	14	100.0
<b>% Selfcare Ability Levels</b>										
0-25 (low)	88	78.7	26	30.6	18	41.0	12	15.8	6	42.8
26-50	11	10.3	12	14.1	10	22.7	6	7.9	0	-
51-75	7	6.5	21	24.7	6	13.6	15	19.7	0	-
76-100 (high)	4	3.7	20	23.5	9	20.5	41	53.9	1	7.1
Unknown	1	0.9	6	7.1	1	2.3	2	2.6	7	50.0
Total	107	100.1	85	100.0	44	100.1	76	99.9	14	99.9
<b>% Developmental Levels</b>										
0-25 (low)	88	82.6	27	30.6	21	47.8	14	18.4	6	42.8
26-50	15	14.0	28	32.9	11	25.0	18	23.7	0	-
51-75	3	2.8	17	20.0	8	18.2	24	31.6	0	-
76-100 (high)	0	-	8	9.4	3	6.8	18	23.7	1	7.1
Unknown	1	0.9	6	7.1	1	2.3	2	2.6	7	50.0
Total	107	100.0	85	100.0	44	100.1	76	100.0	14	99.9

Percents may not total 100% due to rounding.

The majority of deaths (86.5%) were caused by diseases such as pneumonia, cardiac arrest, and so forth. Less than 4% were caused by accidents, and almost 10% of deaths were due to undetermined or unknown causes. Overall, about 60% of deaths were reported to a coroner, and an autopsy was preformed on 66% of individuals who died.

### **Data Abstraction Instrument**

A data abstraction instrument was developed with the goal of providing a comprehensive picture of individual health status, ongoing medical and residential care, emergency care, preventive care, advanced care directives, and contact with family. The instrument was developed based on input from experts in the care of individuals with developmental disabilities, a review of existing instruments, and a review of the literature. The instrument was pilot tested and revised. Experts in the field of developmental disabilities and the California Medical Association Workgroup on Health Care for Persons with Developmental Disabilities reviewed the final product.

### **Procedures**

Registered nurses were hired and trained to abstract data using the data abstraction instrument. Each nurse was screened on her ability to abstract data comprehensively and accurately using a test client record. Inter-rater reliability was established at 85% or higher, using the test client records. Nurses were then sent into the field and further evaluated on their ability to accurately and efficiently abstract client health care data. Supervisors audited 10% of records, comparing their abstracted records with those of the nurses they supervised.

Data were gathered from all available records on clients, including regional center records, residential care facility records, and hospital records as appropriate. Regional center staff helped identify facilities, assisted with access to resistant facilities, and helped locate files from facilities that had moved or closed. When unable to access agencies directly or with regional center assistance, the California Department of Developmental Services attempted to gain agency cooperation through letter and telephone contact. After the data for the panel were

abstracted, a person who did not know the consumer's residential setting pre-screened the file to ensure that there was no information that would reveal the residential setting in the final record.

Finalized records were then each sent to physicians and nurses for review. Records for individuals who had resided in Northern California were sent to expert panelists from out of state or from Southern California, and records of those who had resided in Southern California were sent to panelists from Northern California or out of state. Expert panelists completed an expert panel review form (see Appendix C1), where they rated emergency, preventive, and ongoing medical and residential care. In addition, experts evaluated the use of advanced care directives, the client's role in his or her health status, and the family's role in the client's health status. The majority of expert panelists wrote comments on aspects of the patient's care. These comments were reviewed and coded by two research nurses (see Appendix C2 the coding instrument and protocol). In addition, the research nurses edited the expert review forms to ensure consistency between comments and checked responses. Inter-rater reliability was established between the two research nurses at 90% or greater.

### **Selection of the Expert Panel**

A national panel, which consisted of physicians and registered nurses who were identified as experts in the health care management of individuals with developmental disabilities, was constituted to review the abstracted records. Panel members were selected based on referrals by the California Medical Association, the California Developmental Disabilities Nurses Association, and recommendations by individuals known in the field of developmental disabilities. A number of outstanding professionals from across the nation participated in the review of client records, as can be seen in Appendix D. Expert panel reviewers were blinded to whether the placement was in a community or a state facility. Each record was evaluated by 2 physicians and 2 registered nurses, who rated the care of the individuals. A final rating of the care of each individual was obtained based on a simple majority among the 4 panelists. When a majority was not reached, the ratings of the 2 physicians were considered for quality of medical care management, and the ratings of the 2 nurses for quality of residential care. There were 53 records where no agreement could be reached among the expert panelists. A research nurse was hired to review these records. Where there were questions regarding the quality of medical care, records were reviewed and rated by a DDS physician,

nationally recognized for her expertise in the field of developmental disabilities. This further review resulted in agreement on all but 7 of the 58 records.

## RESULTS

### Research question 1: Did the quality of health care or supervision by physicians or residential staffs contribute to mortality of individuals studied?

A composite overall variable was developed and defined as the worst rating on three items that asked whether the death might have been prevented by better quality in the following specific areas: preventive care, residential care, or health care delivery including both medical and residential aspects. If panelists agreed that changes in any of these areas could have prevented death, the individual's death was rated as preventable.

Expert panelists ratings indicated that residents at developmental centers were significantly less likely to die from preventable causes than those residing skilled nursing facilities, intermediate care facilities, or community care facilities (all p-values less than 0.001).

To further examine the factors that contributed to deaths, all preventable and non-preventable deaths were scrutinized. Panelists agreed that inadequacies existed in the care of 95 clients. Of these 114 clients, 38 deaths were identified as being preventable (see Table 6).

Table 6 Identified Quality of Care							
Living arrangement at time of death	Care Not Adequate					Adequate Care	
	<u>Preventable Death</u>		<u>Death Not Preventable</u>		<u>No problem</u>		
	Number	Percent	Number	Percent	Number	Percent	
DC	2	5.3	5	6.6	88	62.9	
SNF	11	28.9	29	38.2	24	17.1	
CCF	17	44.7	19	25.0	11	7.9	
ICF	8	21.1	17	22.4	11	7.9	
Other CLA	0	-	6	7.1	6	4.3	
Total	38	100.0	76	100.1	155	100.1	

Note: No agreement among panelists for 7 cases. Documentation inadequate in 65 cases. Percents may not total 100% due to rounding.

were being ambulatory, moderately to profoundly mentally retarded, not having CP, and having limited self-care abilities. This is in contrast to findings in research on inherent risk of mortality, which show immobility, having CP, and lacking self-care abilities as risk factors for mortality.

Almost one half of those who died from preventable deaths resided in CCFs. Many of these CCF residents did not have the inherent risks of mortality identified in previous research, such as lacking mobility and self-care skills. The most common characteristics of those who died from preventable deaths

Inadequacies in the quality of medical and residential care were the most commonly noted problems, with inadequacies in residential care twice as likely to be cited as inadequacies in the medical care.

It is important to note that cases of preventable death averaged 4.05 quality of care problems per individual, compared to non-preventable deaths, which averaged 1.44 problems per individual. Problems clustered into three areas, medical care, residential care, and the structure of services.

**Research question 2: Were there differences in the quality of health care or supervision provided to individuals with developmental disabilities by physicians or residential facility staffs based on the type of residential setting?**

The types of medical care problems identified by expert panelists are listed in Table 7. The most commonly noted problem area was inadequate preventive health care, most frequently due to a lack of screening exams, particularly for cardiac disease, and as well as absence of

preventive immunizations for flu and pneumonia. Inadequate medical management and care of health problems were also identified as factors contributing to morbidity and mortality.

<b>Table 7</b> <b><u>Quality of Medical Care Problems for 114 Consumers</u></b>	
<b>Problem Areas*</b>	<b>Number of Consumers</b>
Preventive care did not meet standard	22
Better preventive care could have prevented death	2
Improvements in medical care/prevented death	10
MD medical management inappropriate	25

\*More than one response possible; required agreement of at least 3 Expert Panelists



Missed or delayed diagnoses were the most commonly cited medical management and care problems (see Table 8 for a listing of the types of problems noted by expert panelists). These were followed in frequency by lack of referrals to specialists.

<b>Table 8</b> <b>Types of Medical Care Problems for 114 Consumers</b>	
<b>Problem Areas*</b>	<b>Number of Consumers</b>
Delayed/missed diagnosis	45
Delayed referral to specialist	36
Medication mismanagement	16
Inadequate lab or x-ray	18
Care not aggressive enough	14

\*More than one response possible; required agreement of at least 3 Expert Panelists

<b>Table 9</b> <b>Delayed/Missed Medical Diagnosis by Type of Health Problem for 114 Consumers</b>	
<b>Delayed/Missed Diagnosis*</b>	<b>Number of Consumers</b>
Cardiac	29
Cancer	16
Respiratory general	14
Other gastrointestinal	10
Urinary/renal problems	12
Aspiration/recurrent aspiration	9
Fractures/injury	7
Seizures	7
Weight change	6
Neurological	5
Gastroesophageal reflux disease	4
Constipation/impaction	2
Infection	2
Social/emotional/behavioral	2
Diabetes/other endocrine	2
Fluid management	2
Dysphagia	1
Decubiti/other skin	1
Anemia	1
Dental	1
Vascular	1
Vision	1

\*Inclusion of consumer did not require agreement of 3 or more Expert Panel responses; more than one response possible

Expert panelists identified a series of health problems that were inadequately diagnosed (see Table 9). Cardiac disease was listed the most frequently. Symptoms, such as arrhythmias, chest pains, and apnea were not followed up on with laboratory and x-ray exams. Identified abnormal findings, such as abnormal electrocardiograms, x-rays showing enlarged hearts, and high blood pressure were not addressed with further exams, nor were consumers monitored. In other cases, medication management was inadequate.

In one case, for example, one medical reviewer wrote the following comments in regard to the care provided to a person living in a community care facility, who died of congestive heart failure:

“no BP [blood pressure] measurements? No screening labs. Amoxicillin is not a prescription for CHF [congested heart failure],

put on KCL [potassium] without any labs is of great concern...cardiologist not involved. The medical care received is questionable. Had she had an adequate advocate or guardian who asked questions perhaps her care would have been better & more suited to the seriousness of her condition. The system broke down for this unfortunate woman. This person should have had an autopsy as well.”

Another reviewer wrote:

“I am deeply distressed about the information in this report. If the information is accurate and true, it appears that this individual died as a result of a cardiac condition that was treated by a physician over the phone. No evidence of cardiac work-up or re-eval by MD following CXR [chest x-ray] suggestive of enlarged heart. I am also concerned re: the lack of formal inquiry/autopsy in this case. The level of indifference for this individual’s life & death is very sad.”

Often consumers had multiple health problems, which increased their need for careful medical management. A reviewer wrote:

“Did not obtain adequate monitoring labs. On labs obtained that were abnormal H/H [hemoglobin & hematocrit] progressively lower did not appropriately evaluate and manage. Ulcer and GER [gastroesophageal reflux], with associated anemia, should have been more aggressively managed. Wheezing also probably 2° GER—treated with bronchodilators rather than also providing anti-reflux management. Should have been followed by a gastroenterologist. Also need orthopedic management. No monitoring of LFT’s or nutritional labs (A.f, Prot, Ca++, etc). Needed anti-reflux medication. Should have acted on left shift of CBC [complete blood count] immediately & high fever. Did not diagnose GER/aspiration. If diagnosed earlier with GER, may have prevented aspiration pneumonia →sepsis →death.”

This case is an example of the types of gastroenterology, aspiration, and respiratory problems that were inadequately managed. These problems were often found in the same person.

Inadequate medical management often included a lack of referrals to specialists (see

<b>Table 10</b> <b><u>Delayed Referral to Subspecialist by Type of Specialist</u></b> <b><u>Needed for 114 Consumers</u></b>	
<b>Subspecialist*</b>	<b>Number of Consumers</b>
Cardiology	29
Neurology	26
Gastroenterology	22
Nutritionist/oral motor spec.	22
Pulmonology	17
Psychiatry/psychology	12
Orthopedics	6
Occupational therapy	5
Oncology	5
Endocrinology	5
Speech/audiology	4
Hematology	4
Physical therapy	2
Urology	2
Dermatology	2
Gerontology	1
Ophthalmology	1
Rheumatology	1
Surgeon	1

\*Inclusion of consumer did not require agreement of 3 or more Expert Panel responses; more than one response possible

Table 10), as demonstrated in the above examples. Neurological problems, in particular, were cited as needing to be addressed by specialists. Problems tended to fall into two general categories—inadequate referral of those with seizures and inadequate referral of those with hydrocephally. Problems with seizure management often were in regard to inadequate management of anti-convulsants. As one reviewer wrote: “If terminal event was related to ‘flu’ then flu shot would have helped. Physician was treating client based on ‘poor prognosis’ early in care. However, client did show signs of improvement but care did not increase to assist in rehabilitation. Treatment of seizures also needed to utilize newer anticonvulsant agents than Phenobarbital, which could have

diminished her cooperation due to sedation.” Physicians were critiqued for not addressing low serum drug levels, poorly controlled seizures, and changing medications without responding to adverse consumer responses to changes. Problems with inadequate management and referral of hydrocephalus were delayed follow-up on initial diagnosis, lack of referral and monitoring by a neurologist, and inadequate physician response to symptoms of shunt failure or infection.

### **Quality of residential care concerns.**

The most commonly cited residential facility care problems were inadequate management of medical problems, lack of nursing management, and not recognizing acute illness changes (see Table 11). Poor residential care management is exemplified in the case of a profoundly mentally retarded individual who lacked communication skills, and had cerebral palsy with very limited mobility and self-

<b>Table 11</b> <b><u>Residential Care Issues by Type of Care Problem for 114 Consumers</u></b>	
<b>Care Issues*</b>	<b>Number of Consumers</b>
Didn't recognize acute illness changes	74
Lack of medical management	68
Lack of nurse management	67
Didn't follow care plan	32
Didn't provide appropriate treatment	30
Delayed MD contact	26
Didn't give prescribed medicine	14
Delay transfer to higher level of care	12
No/limited support	4
Care not provided if inconvenient	5
Missed MD appointments	4
Lack of advocacy	3

\*Inclusion of consumer did not require agreement of 3 or more Expert Panel responses; more than one response possible

client's health needs. Better management of this person's medical problems and management of their health care needs by a nurse could have prevented their death.

The types of health problems most likely to be inadequately managed by residential facilities were decubiti, aspiration, and cardiac problems (see Table 12). A middle-aged individual became non-ambulatory following a joint replacement. Expert panelists were concerned about the overall care of this person. There was no documentation of physical therapy to encourage ambulation. This person was a diabetic, with poor glycemic control, and had multiple decubiti on his back and feet. Death was due to septicemia. As one reviewer commented, "Patient with multiple pressure ulcers should have been in a special step-down bed and had frequent position changes -- up in a special padded chair, etc."

care skills. This person had ongoing problems with bowel obstructions, including several episodes in the last year of life. The person was found non-responsive, and pronounced dead a short time later. A bowel obstruction had resulted in a severe electrolyte imbalance, leading to death. The expert panelists noted that there was no treatment plan in place for the individual's chronic bowel obstructions, nor was there evidence that the client had been followed by a gastroenterologist. Of additional concern was the absence of documented symptoms prior to the person's death, indicating a lack of attention to this

**Table 12**  
**Residential Care Issues by Type of Health Conditions for 114 Consumers**

Health Conditions*	Number of Consumers
Decubiti	9
Aspiration	7
Cardiac	7
Respiration, general	5
Allergy	5
Nutrition	5
Fractures	4
Dysphagia	3
Fluid Management	3
Other GI	2
Seizures	2
Urinary	2
Neuro/shunt	2
Gastroesophageal reflux disease	1
Constipation	1
Diabetes	1

\*Inclusion of consumer did not require agreement of 3 or more Expert Panel responses; more than one response possible

Aspiration was generally associated with feeding problems. Expert panelists critiqued the quality of feeding care plans, and the absence of attention to factors associated with recurrent aspiration. In addition to expressing concern about the need for better management of health problems in residential facilities, panelist's frequently indicated that no one was advocating for consumer health needs. Inadequate treatment of cardiac problems, for example, was not addressed by residential care

providers who could have advocated for more aggressive care.

Failing to meet consumer safety needs was another key problem area identified by expert panelists (see Table 13). As a consumer's status changed due to problems such as increased seizures or confusion, there were not corresponding changes in supervision of the consumer. Similarly, efforts were lacking, in some cases, to protect consumers from ingestion of foreign objects, or from choking on food. Other types of problems were not

**Table 13**  
**Residential Care Problems by Safety Issues for 114 Consumers**

Safety Issues*	Number of Consumers
Supervision not increased with behavior change	31
Wasn't protected from dangerous behaviors	14
Safety supervision	188
Didn't respond to adverse medication reaction	8
Restraints used	5
Equipment problems	3
Positioning	2

\*Inclusion of consumer did not require agreement of 3 or more Expert Panel responses; more than one response possible

encouraging consumers to use safety equipment such as a headgear. CCFs were the most likely type of facility to be cited for safety problems, particularly for preventable deaths. Often individuals with chronic health problems, such as seizure disorders, were inadequately supervised, even when behavioral changes warranted closer supervision. Lack of adequate supervision resulted in deaths due to drowning, aspiration, or injury.

### **Adequacy of Documentation.**

Data were sought from all available client records, including residential records, regional center records, and, as appropriate and available, hospital records. All data were recorded in the abstracted files as found in existing client records. Of the 345 clients selected for the sample, no records were available on 19 of them, 4 having been destroyed in fires, and 15 could not be located. As can be noted in Table 14, DCs were the most likely type of facility to have adequate documentation, followed by SNFs. CCFs were the least likely type of facility to have adequate documentation.

Table 14									
<u>Adequacy of Documentation by Type of Residence</u>									
Living arrangement at time of death	<u>Inadequate documentation</u>				<u>Adequate documentation</u>		<u>No agreement</u>		Total
	Too little information		Information with gaps						
	Number	Row Percent	Number	Row Percent	Number	Row Percent	Number	Row Percent	
DC	5	4.7	8	7.7	89	83.2	5	4.7	107
SNF	15	17.6	34	40.0	36	42.4	0	0.0	85
CCF	19	25.7	35	47.3	17	23.0	2	2.7	74
ICF	6	13.6	21	47.7	17	38.6	0	0.0	44
Other CLA	4	25.0	8	50.0	4	25.0	0	0.0	16
Total	49		106		164		7		326

More than 95% of DC residents had evidence of care plans whereas such plans were present in only about 21% of the CCFs. In the DC records, 53% of the care plans were rated as good or excellent, compared to about 6% of the CCF care plans (see Table 15, following page).

<b>Table 15</b>										
<b><u>Rating of Care Plan</u></b>										
<b>Rating of Care Plan</b>	<b>Living arrangement at time of death</b>									
	<b><u>DC</u></b>		<b><u>SNF</u></b>		<b><u>CCF</u></b>		<b><u>ICF</u></b>		<b><u>Other CLA</u></b>	
	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>
Not adequate	3	2.9	15	36.6	8	50.0	8	36.4	1	20.0
Adequate	14	13.7	7	17.1	7	43.8	6	27.3	2	40.0
Good/excellent	67	65.7	9	22.0	1	6.3	3	13.6	2	40.0
No agreement	18	17.6	10	24.4	0	0.0	5	22.7	0	0.0
Total	102	99.9	41	100.0	16	100.1	22	100.0	2	100.0

Percents may not total 100% due to rounding.

### **Structure of Services**

Expert panelists identified inappropriate insurance restrictions for two of the 95 consumers noted to have problems with the quality of care provided to them. Both of these deaths were considered preventable had the insurance carrier authorized timely access to specialized services. In one case access was denied to a specialty center, and authorized for a facility with less experience in conducting a procedure the patient needed. Within two months the patient needed corrective surgery for the procedure, and failed to thrive after this final surgery. In three additional cases consumers were residing in a lower level of care than experts felt they needed.

**Research question 3: Did the consumer's or family member's wishes contribute to mortality?**

**and**

**Research question 4: Did Advanced Care Directives play a role in preventable mortality?**

To assess the possible influence of choices made by clients or their family members, analyses were repeated excluding all clients who had special care directives, whose refusal to comply with medical care, or whose lifestyle choices or actions, may have contributed to death. Also excluded were clients whose family choices regarding medical management, hospitalization, or treatment may have contributed to death. Neither topic appeared to be related to mortality. This process excluded 138 persons, but did not result in any large changes in results, with care in developmental centers still rated significantly higher than care in community settings (see Appendix E for complete results).

## **SUMMARY AND DISCUSSION**

### **Comparison of the Quality of Care**

This study collected detailed data on the types of services received by consumers in various kinds of settings, and used expert panelists to rate the quality of health care for the sample of persons who had died. Inadequate health care may have a greater impact on individuals with developmental disabilities than those without disabilities because of their increased vulnerability (Walsh and Kastner, 1999). Analysis of client data provided the opportunity to review how quality of care influenced the mortality of the individuals studied. It also offered the opportunity to review quality of health care provided to those who died.

Quality in health care can be evaluated by examining four domains: structure, process, outcomes and satisfaction (Pulcini & Howard, 1997; Walsh & Kastner, 1999). The first two, structure and process, are measured by evaluating the system of care (Walsh & Kastner, 1999), which was the focus of this study, the outcome being mortality.

### **Deficiencies in the Structure Domain**

The structure domain is defined by Walsh and Kastner (1999) as the “physical and administrative context within which health care is delivered, including the facilities, equipment, supplies, staff, and policies and procedures of a health care organization” (p. 3). Two areas addressed in this study fell within this domain: availability of specialty services and insurance restrictions.

### **Availability of specialty services.**

Studies have shown that individuals with developmental disabilities are likely to have more complex and persistent health problems than other populations (Baeange, et al., 1995; Kapell, et al., 1998; Zirig, et al., 1988). Access to specialty services, particularly those provided by a physician with expertise in serving this population, is needed by this population to adequately address these problems, but has been found to be limited in community settings (Ziring, et al., 1988).

This finding was verified by our study. Expert panelists agreed that a number of consumers should have been seen by specialists, the most common being cardiology, gastroenterology and neurology. Indeed, in some cases the panelists suggested that timely examination and treatment by a specialist, particularly a cardiologist, might have postponed or



forestalled the death. Whether lack of referrals was due to a lack of specialists available within the providers' network (a structural problem) or due to a lack of recognition of the need for specialty services (a process problem) was beyond the scope of this study.

### **Insurance restrictions.**

Walsh and Kastner (1999) point out that access to specialty centers with expertise in care of individuals with developmental disabilities is important for ensuring adequate quality of care. Concerns have been raised that attempts by insurance providers to control costs of care may result in restricted access to such centers. This was not an issue in this sample. In 1994, only two individuals' deaths may have been related to insurance restrictions.

### **Quality Deficiencies in the Process Domain**

Process is defined as "How health care is delivered and the things done to or for the patient, including access, coordination, clinical care, and timeliness" (Walsh & Kastner, 1999, p.4). The bulk of expert panelists' concerns pertained to process issues, with most focusing on the quality of medical and residential services.

### **Medical Services**

Ensuring provision of quality medical care for individuals with developmental disabilities has been an ongoing concern as individuals have been transferred from state facilities to community-based facilities (Criscione, et al., 1993; Kastner, et al., 1997; Minihan, 1986; Zirig, et al., 1988). Findings support contentions that community-based primary care physicians may not be adequately prepared to care for the types of chronic health problems individuals with developmental disabilities may have (Kapell, et al., 1998; Zirig, et al., 1988). Cardiac problems, the type of problem most likely to be cited by the expert panelists for being poorly managed, have been identified in previous studies as being under-diagnosed and inadequately treated (Zirig, et al., 1988; Kapell, et al., 1998). Respiratory illnesses are commonly associated with individuals with disabilities, particularly those with limited mobility. It is essential that primary care physicians be knowledgeable about the best practices for treating respiratory problems. They also need to recognize the influence of environmental factors, such as feeding practices of caregivers, on chronic respiratory problems. One case reviewed for this study was a child who was treated 6 times in as many months for respiratory infections. Each incident was treated separately and no attention was given to the repeat nature of the illnesses. In this case, the

etiology was probably due to aspiration during feedings, but this was never investigated. If primary care physicians are expected to care for individuals with developmental disabilities it is essential that they be educated in the ongoing management of chronic and persistent illnesses common to this population.

Another area needing further attention is the provision of preventive health care services. Individuals with developmental disabilities should receive screening exams and tests with at least the same frequency as the general population. Use of electrocardiograms on symptomatic persons and those over 50, as well as blood pressure screening and monitoring, for example, could have led to earlier diagnoses of cardiac problems. Ongoing tracking of preventive health services is needed to ensure adequate access of individuals with developmental disabilities to preventive health care.

### **Residential Services.**

Expert panelists cited deficiencies in the quality of care in residential services more frequently than any other area addressed in this study, and twice as often as deficiencies in the quality of medical care. Although, as noted previously, concerns about access to quality medical care are frequently cited in the literature, deficiencies in the quality of health care services in community-based residences are infrequently addressed. Previous studies regarding quality of residential care services have focused extensively on improvements in the quality of life of individuals residing in community-based residential facilities versus those residing in state facilities (Stancliffe & Lakin, 1998; Walsh & Kastner, 1999). Only one study (Heller, et al., 1998) indicated that physical health was better for those residing in community facilities, and their definition of physical health was very limited. We could find no previous studies that attempted to measure the quality of residential services and its impact on mortality.

In this study we focused on the quality of health care provided in residential facilities. Client records were reviewed and all data related to ongoing identification and management of health problems were abstracted. Findings indicate that inadequate management of residents' medical problems, lack of nursing management, and failure to recognize acute illness/behavioral changes were the most frequently noted types of residential care problems. Consumers had health problems common for this population, such as recurrent pneumonia, ducubiti, and poorly controlled seizure disorders. These problems can be readily addressed with care plans that

carefully delineate daily care to treat or prevent ongoing health problems. There was a lack of evidence of well thought out plans of care and documentation failed to show early recognition of illnesses & deterioration in health status for those living in community-based facilities.

Individuals living in CCFS, who are generally ambulatory, tended to not receive needed cardiac assessments and treatments. Similarly, there was a lack of appropriate management and referral for individuals with poorly controlled seizure disorders. In addition, there was a lack of assistance to help residents adapt to chronic health problems such as diabetes and asthma. Safety issues were the most commonly cited problems for CCFs, particularly for preventable deaths. As individuals developed poorly controlled seizures, for example, they were not supervised when bathing in spite of the danger of drowning nor was there evidence of efforts to encourage them to wear safety equipment. There seemed to be a conflict between intervening and allowing self-determination. Caregivers indicated that they did not consider oversight of consumer health problems as part of their role, since consumers living in CCFs were expected to be somewhat autonomous. In general, there was a lack evidence of ongoing case management or advocacy for health services and care for this population.

There were clear differences in the way services were provided by type of residential facility. Care plans, in particular, were not evident in many CCF records. Less than one quarter of the care plans were rated as “good/excellent” by the expert panelists. The DCs were the most likely type of facility to have highly rated care plans. Careful care planning by interdisciplinary teams have been shown to improve functional health outcomes in frail elderly and may be of similar value for medically fragile individuals with developmental disabilities (Covinsky, et al., 1998).

There was evidence, in their annual reviews of client services, that regional center staff routinely included a goal that clients be seen by their primary care physicians for health exams and that physicians’ recommendations for care be followed. These goals were generally generic, with little variation from year-to-year. The regional centers’ involvement in health care generally focused on responding to requests from residential care providers or clients’ family members. Residential care facilities seemed to have autonomous authority to decide what specialty services were needed, who should provide the services, and how much effort should be put into pursuing specialty services. Only family members had a greater influence on the choice of services. In many cases there was no evidence of anyone providing oversight on the quality and degree of services clients received.

Findings indicate that a great deal more research is needed to document what factors are influencing the quality of care in residential facilities. As parents and their children age, and the need for residential services increases (Braddock, 1999), assuring access to facilities that provide the type of care consumers, parents and advocates feel confident of will become increasingly important. Study findings support Borthwich-Duffy, et al.'s, (1998) point-of-view, "If there are serious deficiencies in quality of care, in any setting, we must identify them and remedy them, and we must establish careful monitoring procedures to ensure continuing quality of care. We must also develop more accurate estimates of health risk factors and examine carefully the influence of different aspects of care provided in different residence types on morbidity and mortality" (p. 418). Effective care management can reduce costs associated with the care of individuals with developmental disabilities, whose health problems result in higher utilization of out-patient and hospital care and pharmaceuticals than other populations (Criscione, et al., 1993; Kastner, et al., 1997a; Kastner, et al., 1997b; Zirig, Kastner, et al., 1988). Efforts to educate providers and residential facility staff have shown that care can be provided in community settings in a safe and effective manner to those with complex problems (Litzinger, et al., 1993). Service systems using nurse practitioners as care managers have been able to reduce hospital stays, decrease unnecessary hospitalizations, decrease the severity of illnesses, and lower the costs of care (Criscione, et al., 1993; Kastner, et al., 1997a; Kastner, et al., 1997b; Zirig, Kastner, et al., 1988). These elements of services need to be explored more fully in California.

#### **Family & Consumer Choices/Emergency Response**

Family and consumer choices did not differ significantly by type of setting. Similarly, emergency responses were the same in various community settings. Neither set of factors seemed to be particularly related to mortality or morbidity in this population.

### **Limitations and Strengths of the Study**

Since this was the first study of this scope, there was a lack of models to draw upon for designing data abstraction instruments. Therefore, in some cases, more data were gathered than needed, and less data than needed were collected in other areas. Accessing 1994 data in 1997 was problematic, since some records had been destroyed, or lost, and facilities had closed. Findings were limited to data available, and in some instances, documentation on consumer care was minimal. Although hospital data were accessed, physician office records were not accessible.

A national panel was selected to avoid any possible conflict of interests that could have been an issue if all panelists were from California. Outstanding national experts participated in this review, but their geographic distance prohibited bringing them together to resolve disagreements. Bringing the reviewers together to discuss their ratings would not only ensure quick resolution of differing views, but would also serve as an opportunity to develop consensus on the issues and problems identified in a study. An additional problem encountered with the approach used was the slow and tedious pace of the review process. The majority of experts are highly committed to their profession and each record review took approximately 1 ½ hours. They were each asked to review 50 records, and it took over 1 ½ years to complete the expert panel reviews.

This study was the first effort of this scope and intensity. Extensive efforts to gather comprehensive data, which were combined with existing data sets, allowed us to begin to document the quality of care received by consumers in various kinds of settings. A preliminary picture of the quality of services statewide was developed. However, analysis suggests that other aspects of the quality of residential services need to be included in subsequent studies.

In spite of limitations, findings were clear and consistent. Analysis of findings allowed us to get closer than any prior study to answering questions on the relative importance of various factors – person characteristics, environmental characteristics, and living arrangements – in mortality.

## **CONCLUSIONS AND RECOMMENDATIONS**

Research on quality of care issues in services for individuals with developmental disabilities has primarily focused on the quality of life, concentrating on social and community contacts and activities. The quality of health has typically not been addressed with any depth (Walsh & Kastner, 1999). Studies of health have focused on the use of large data bases, such as the CDER, to identify causes of death, residential status, and the personal characteristics of those who died. This does not allow us the opportunity to compare the quality of health care in various kinds of settings, or to examine the impact of the quality of care on outcomes such as mortality (Hayden, 1998). This study is a beginning step toward measuring the impact of the quality of health care on individuals with developmental disabilities.

Most problems were related to the delivery of care and management of health problems commonly found in individuals with developmental disabilities. No preventable deaths were from unusual diseases or injuries. Preventable deaths were not related to clients' inherent risks of death due to their disabilities. Rather, preventable deaths were most frequently associated with inadequacies in the quality of care provided in residential settings, followed by inadequacies in the medical management of common health problems.

This study demonstrates that review of quality of care is particularly important for individuals with developmental disabilities because they tend to have multiple, persistent health problems. A person with profound mental retardation, limited mobility, and cerebral palsy is likely to have problems with constipation, recurrent respiratory problems, and skin disorders. Each problem impacts the other, and they must be looked at all together, rather than as isolated incidences. For example, if an immobile person develops severe constipation, they are more likely to aspirate, with subsequent development of respiratory disease. Treating one without the other will not effectively improve the individual's overall health status. In addition, one must examine the care provider's quality of care. Are chronic respiratory problems, for example, secondary to poor feeding practices? Are individual's with gastrostomy tubes being fed while lying flat, or being fed too large amounts too quickly? Are care providers trained to feed individuals with swallowing disorders safely? Are staffing ratios adequate to allow the necessary time needed to care for individuals with multiple complex problems? It is essential to examine the interplay of each disease process the individual either has or is subject to, in the

context of their functional status and the care-giving environment. The complex, interwoven, cumulative nature of their problems merits consideration of a more intense and sophisticated service delivery model than that available to the general public (see Appendix F for comparison of death rates for individuals with developmental disabilities to the general population).

A number of studies indicate that the quality of life is better in community settings. The challenge before us is to identify methods to improve the quality of health care management in community settings. Although attention to improving medical care services has been addressed in previous studies and reports, greater attention needs to be focused on improving ongoing care management in residential facilities.

**Based on the study findings, we recommend the following:**

1. Support efforts to promote preventive health care, particularly screening exams for cardiac functioning. Promote all types of vaccinations including those for flu and pneumonia.
2. Continue the Department of Developmental Services' efforts to educate physicians and other health professionals on caring for individuals with developmental disabilities. Additional monitoring is needed to ensure that these efforts adequately address the need, especially for treatment of complex and inter-related health problems.
3. Ensure availability of specialists for this population. Their health problems need to be monitored and interventions made as needed to ensure adequate oversight by experts in specialty fields such as cardiology and neurology.
4. Intensify oversight and client-specific training for residential care facilities. Monitor training needs, educational efforts, and provide multidisciplinary technical assistance programs to improve the level of care in these settings. This is particularly true for community care facilities, where care providers may have little expertise in health care management.
5. Training needs evident based on this study include the following:
  - Addressing the persistent, complex and inter-related nature of many health problems (cardiac, aspiration, pneumonia, constipation, and so forth)
  - Recognizing changes in health status

- Appropriate responses to health status changes, such as contacting a supervisor or a physician
  - Meeting safety needs of those with developmental disabilities
  - Documenting and monitoring consumer health needs and safety
  - Development and use of care plans
6. Provide multidisciplinary teams (such as physicians, nurses, physical therapists, and nutritionists) to assess and monitor consumers with multiple, chronic health problems.
  7. Ensure that Regional Centers have effective mechanisms for identifying consumers whose health care needs require close monitoring or supervision, and for bringing these consumers to the attention of clinical team members for appropriate intervention and follow-up.
  8. Increase nursing case management of consumers with chronic, persistent health problems. Activities should include developing screening systems to identify persons most in need of nursing case management, development of care plans that are written at a level and with such detail that they can be used effectively by residential staff, coordinating with primary care physicians, providing training to residential services staff, and monitoring the quality of health-related services provided in residential settings.
  9. A system of ongoing monitoring and advocacy is needed to ensure that care for individuals with developmental disabilities is aggressive enough. The current system relies too heavily on residential care providers whose expertise is often too limited to ensure adequate oversight of overall care. Overburdened health care systems, designed to treat populations capable of self-advocacy, generally have staff with limited expertise in managing the complex care of individuals with developmental disabilities. In addition, they lack the support needed to safely monitor and manage the care of individuals with such complex health problems and such limited advocacy capabilities. A system of ongoing monitoring and advocacy could ensure that those living in community-based facilities receive the type of health care they need.
  10. Mortality reviews provide important data on the quality of services provided individuals with disabilities and should continue. However, they should be supplemented with



prospective studies of living individuals to document how different approaches to services can improve health outcomes.

Finally, it is important to point out that these deaths occurred in 1994. Since that time the Department of Developmental Services has launched a “Wellness Initiative” and taken many actions to improve the health care services received by persons living in community settings.

This includes:

- Expanding the availability of staff with clinical expertise at the regional centers by authorizing “clinical teams” consisting of physician, nurse, behaviorist, and often a pharmacologist at each center.
- Providing training to residential care staff on health care issues including recognizing signs and symptoms of illness and responding to changes in the consumer’s health status.
- Providing training to regional center case managers on identifying consumers whose health care needs require the assistance or intervention of clinical team members.
- Working with the California Medical Association to provide training to physicians in issues related to developmental disabilities, including establishing a module on developmental disabilities at one medical school.
- Providing on-line information about developmental disabilities for use by physicians throughout the State.

Anecdotal reports indicate that these and many other health-related actions by the Department and the regional centers have had a positive impact on the quality of health services received by consumers. CSUS is conducting a companion study to this one, examining deaths that occurred in 1999. It is hoped that the new study will show fewer deficiencies in the residential and medical management of services for persons with developmental disabilities as the result of these actions.

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METHODOLOGY FOR IDENTIFYING AND VERIFYING 1994 DEATHS AMONG  
PERSONS WITH DEVELOPMENTAL DISABILITIES SERVED BY THE  
DEPARTMENT OF DEVELOPMENTAL SERVICES

Primary Match

The Department of Developmental Services (DDS) matched records of persons on its Client Master File (CMF) as of 01/11/95 to records on a death file from Vital Statistics (VS). The match was conducted using SAS software to generate an algorithm based on the sound of the last name. Using this classification scheme, vowels and the letters “Y,” “W,” and “H” were deleted from the last name. The first letter of the last name became the first of four characters which made up the “sound” representation. Consonants on the last name which have a similar sound, such as “P” and “B” or “T” and “D” were given similar values (1-6). The same procedure was performed for the second, third, and fourth consonants in the last name. The results was a four character code such as “W142.” Both the CMF and VS files were subjected to this process. A variable was then constructed which took the code and appended and the birth date (in the form of MMDDYY). Both files were then sorted by this new variable. Using the example above, the resulting “code” might have been “W142021249.” The two computer files were then “match-merged” using the new variable or code.

Next, using SAS, social security numbers on each matched record were examined. If the social security numbers did not match, each digit in each social security number was examined and if seven or more consecutive digits were identical, then the numbers were considered to match. If the social security numbers still did not match, one social security number was subtracted from the other and, if the difference was divisible by nine with no remainder, the assumption was made that one of the social security numbers contained a transposition error.

Then, the first three letters of each last name and the first three letters of each first name were compared to eliminate matches where names were similar, but clearly different for persons who had active case status codes of 1,2, 7, or 8. If a regional center (RC) or developmental center (DC) had reported the person had died and the CMF and VS match showed concurrence of death, no further verification was done. The person was considered to have died. Where an RC or DC had not reported the person was dead, or the CMF and VS match was less than perfect, then the person was put in a “questionable” category.

### Survival Verification

The 505 persons classified as “questionable” were sorted by RC or DC and sent to those agencies for verification. RCs and DCs were asked to verify whether the individual in question was indeed a RC or DC client within the period 01/01/94 through 12/31/94 and, if so, whether the individual was deceased. RCs also were asked to verify that the individual’s status was “active” client at the time of death. This was done because the Client Master File contains records of everyone who has ever been an RC client, including persons who stopped receiving any RC services years ago. This process resulted in a list of actual RC or DC clients who were known to have died in 1994, plus a list of “mismatches” were people who showed up on the VS file but who were no RC or DC clients. Typical reasons for mismatched names were common names for two different people, twin with the same last names, deceased parents who had substituted their own social security number for their child’s, duplicate Unique Client Identifiers (UCIs). Names with incorrect status codes and/or persons who were incorrectly matched were deleted from the final list of persons who had died in 1994.

Further verification of vital status in 1994 was initiated by the statistical consultant for those persons who would be relevant for planned statistical analyses. These included those for whom demographic and other personal data were available from at least on CDER in the four years from 1991 to 1994, and excluded those born after 12/31/93, who died before 1/1/94, or who were residing in unusual settings such as jails and prisons. Of some 116,745 such persons, 105,757 were verified to have lived through 1994 by virtue of having a CDER that had a report date after 3/31/95 or having an active status code on the May 1998 CMF. There were 10,003 persons for whom death or survival through 1994 remained unverified. These cases were then examined by DDS in the Spring of 1999 to ascertain active client status and survival.

[Note that no attempts were made to ascertain additional deaths among persons who would not contribute to statistical analysis because they did not have CDERs.]

The next step determined whether or not the CMF record had a date of death and, if so, what year the death occurred. If the date was prior to 1994, the client was eliminated from statistical analyses. If the date was during 1994, the client was counted as an additional death. If the date was 1995 or later, the client was counted as a survivor. Next, duplicate UCI numbers were identified and eliminated from the analyses. Since some RCs used the client’s address field to record death information before the “date of death” field was added to the CMF, the address field also was checked for death and/or date of death information.

If an individual’s CMF record showed an updated assessment or eligibility determination after 1994, he or she was considered a survivor. If the CMF record showed that the RC found the person to be ineligible for services before or during 1994, he or she was eliminated from the analyses.

Next, CMF records with status changes, other than death, dated June 30, 1995 or later, were counted as survivors. All CMF records with an out-of-state address and a concurrent “closed-case” status code were identified in order to recognize individuals who moved out-of-state before and during 1994. Records with such moves were eliminated from the analyses.

In order to identify previously unrecognized recorded 1994 deaths, the dates of status change linked to the death status code on the CMF were analyzed. For CMF records with a changed death code (7) status, but no recorded date of death, the date of change in the death code status was used to identify and sort records into the following time periods: 1993, 1994, early in 1995, late in 1995 or later. Only records with a date of change to a death status that was more recent than the date of the prior status change were used. Records with a death status date change in 1993 were eliminated from the analysis. The others were investigated further.

CMF records where either the client or the record became inactive prior to 1994, for reasons other than death, were identified and eliminated from the analyses; records are inactivated by RCs to purge them from their local system when the UCI does not reflect an active client. These cases were identified by searching for records where date of status change was more recent than the date of a prior status change and, no other more recent date activity was present on the record. Next, eligibility determinations and assessment date fields were reviewed to identify activities completed during 1994 as a way of confirming active client status for potential survivors through 1994.

CMF records which were still unclassified as either “active” client (vs. inactive as of 1994 or earlier) or death status, or where there was only a determination of “alive” during 1994 [(signs of dated client activity on one or more file records)], were then matched with CDER six-month files from December 1993 through December 1998. If updated CDER records were present in December 1995 or later, the clients were classified as survivors. If no CDER was present after 1994, and the CMF indicated a 1994 inactivation date and CDER had been present in December 1993 and/or June 1994, then they were eliminated from the analyses. Where December 1993 was the only CDER, and CMF dates were inconsistent with in with inactivation during the first half of 1994, individual Purchase of Service (POS) queries were made. CMF records with a recorded POS activity consistent with survival through 1994 were classified as survivors and those with POS activity consistent with inactivation before the end of 1994 were eliminated from the analyses.

During the summer of 1999 the above analyses were repeated on current CMF data. Additional analyses were conducted to resolve the rest of the 4,063 uncertain cases. Special Incident Reporting of deaths were checked; 1995 death reports confirmed that individuals survived 1994. Confirmation that an individual left the system during 1994, with no confirmation of their death by matching CMF with VS files for deaths 1991 through 1995, resulted in the case being excluded from the analyses. Confirmation that an individual left the system during 1995 or later, with no confirmation of their death by matching CMF with VS files for deaths 1991 through 1995 resulted in the individual being classified as a survivor. The remaining cases were classified as survivors if they had a 1995 or later date of death. If the confirmed date of death was in 1994, the case was added to the list of deaths in 1994. Some cases were eliminated from The analyses with verified dates of death in 1991, 1992 or 1993.

Individual CMF and POS queries were undertaken. Some cases were identified as survivors bases on data consistent with leaving the system in 1995 or later, some as 1994 deaths when there were both a death status code 7 and POS activity ending date consistent with status date.



Other cases were excluded from the analyses because their status changed to inactive during 1994 or late 1993. Of the remaining death status code 7 cases, a case-by-case query of the VS death file was conducted for years 1993 through 1996. Additional probable matches were found in cases where the birth date differed by a day or two or where there were variations in spelling of the last name or where there were reversals in the first and middle names. Case-by-case confirmations were made by matching on the social security number, and/or the actual date of death if it was consistent with the CMF death status change date. Matches were made on birth dates and similar name and zip code. Finally, for the few remaining cases where a match could not be made, telephone calls to the client records section of each regional center were made to verify status code 7 and date of death. For several of the cases where CMF death status code existed but there was no match on the VS file, it was determined that the individual was an active client who died out-of-state or out-of-country. Names are stripped from the VS records for out-of-state-deaths. Telephone calls with regional center staff confirmed survival, 1994 deaths and having left the system prior to 1994.

Of the 10,003 records that were subjected to above procedure, it was determined that 5,053 lived through the end of 1994, 129 died during 1994, and 4,861 were not active eligible clients throughout 1994 and should be excluded from the analyses. This left an uncertain status for 26 cases where no additional information was found to confirm probable death status (0.3 percent of original group). The following table demonstrates the steps resulting in these numbers.

CHECK	NUMBER CHECKED	EXCLUDE FROM ANALYSIS*	DIED 1994	SURVIVED**	UNCERTAIN
INITIAL MATCH	ALL	0	1,254	NOT DETERMINED THIS STEP	505
NO CDER	350	350	275	0	75
CDER REPORT DATE AFTER 3/31/95 OR "ACTIVE" CLIENT STATUS ON CMF MAY 1998	116,745	985	0	105,757	10,988
CMF/CDER/POS ACTIVITY CHECKS 5/99	10,033	1,361	7	4,572	4,063
SIRS	401***	0	0	14	4,049
CMF/VS MATCH 1991-1996, ACTIVITY RECHECK AND VS QUERIES 7/99	4,049	3,374	41	414	220
POS QUERIES	220	123	7	48	42
RC CALLS	42	3	8	5	26
All 1999 CHECKS	10,003	4,861	129	5,053	26

\*Died or otherwise became inactive prior to 1994 with no signs of reactivation in CDER or CMF files, or was never an eligible client or had not become an eligible client before 1/1/94, or was a duplicate UCI number of a number included in the analyses elsewhere. During 7/99 checks, if they left the system in 1994 without return and no evidence suggesting death, they were excluded from the analyses.

\*\* Based on activity in 1995, 1996, 1997, 1998 and/or 199 shown on CMF, CDER and/or POS. Deaths as of 1995 and later would be included here.

\*\*\*May 1999 checks indicated deceased, but not when.

Table B1  
Proportions of Person-Years Classified as High, Intermediate, and Low by Skill Variables and Corresponding Mortality Rates (in %)

(Replication of Strauss et al, (1994), American Journal of Public Health, 86 (10): 1422-1429)

Skill	Person- years	Mortality rates
<b>Motor</b>		
Ambulation		
Low: does not walk	9.9	4
Intermediate: walks with support/walks steadily alone at least 3.05 m	13.7	3.6
High: walks well alone at least 6.2 m, balances well	76.5	1.3
Rolling and sitting		
Low: does not lift head when lying on stomach	1.4	6.7
Intermediate: lifts head when lying on stomach/rolls from side to side or front to back/maintains sitting with minimal support for $\geq 5$ minutes	7.7	4.2
High: assumes and maintains sitting position independently	90.9	1.6
Crawling and standing		
Low: does not crawl, creep, or scoot	5.9	4.6
Intermediate: crawls, creeps, or scoots; pulls to standing/stands with support at least 1 minute/or unsteadily alone for 1 minute	14.2	3.5
High: stands well alone, balances well for at least 5 minutes	79.9	1.4
Arm use		
Low: no functional use of arm	1.2	4.5
Intermediate: moves arm, but does not extend/or partially extends	9.1	3.1
High: fully extends arm	89.7	1.7
Hand use		
Low: no functional use of hand	1.8	4.2
Intermediate: ranking motion or grasps/uses thumb and fingers in opposition	14.4	2.8
High: uses fingers independently of each other	83.8	1.7
<b>Self Care</b>		
Eating		
Low: does not feed self, must be fed completely	4.8	5.5
Intermediate: attempts to finger feed/finger feeds/feeds self with spoon and fork with spillage	35.7	2.4
High: uses eating utensils with no spillage	59.4	1.3
Toileting		
Low: not toilet trained or habit trained	8.4	4.1
Intermediate: habit trained/indicates need/goes by self needs help	24.9	2.8
High: goes to toilet by self, completes by self	66.7	1.3
Bladder control		
Low: no control	8	4.5
Intermediate: some control/control during day only	17.6	3.4
High: complete control	74.4	1.2
Bowel control		
Low: no control	7.5	4.5
Intermediate: some control/control during day only	10.7	4.5
High: complete control	81.8	1.3
Dressing		
Low: does not put on any clothes by self	6.2	4.7
Intermediate: cooperates in putting clothes on/puts some on self/puts on clothes but does not do details	40.1	2.5
High: dresses self completely including all fasteners and other details	53.7	1.1
<b>Mental retardation level</b>		
Mild	40.3	1.4
Moderate	24.6	1.9
Severe	15.9	2.6
Profound	18.5	2.3
Suspected/other	0.7	4.1
Tube feeding		
No, does not have feeding tube	99.1	1.9
Yes, has feeding tube	0.9	6.5
<b>Placement (Health Facility includes Skilled Nursing Facility)</b>		
Community care	39	1.6
Own home	35	1.1
Health Facility	13.5	4.6
Developmental Center	12.4	2.3
<b>Placement (Skilled Nursing Facility separate)</b>		
Community care	39	1.6
Own home	35	1.1
Health Facility	8.9	2.1
Skilled Nursing Facility	4.7	9.3
Developmental Center	12.4	2.3
<b>Age group</b>		
40-49	58.8	1
50-59	23.9	2.1
60-69	11.5	3.5
70+	5.8	7.4

Appendix B1

Table B2

Person-Years (n=17, 140) by Age Group and Subject Characteristic(Replication of Strauss & Kastner, (1996) American Journal of Mental Retardation, 101 (1), 26-40)

Characteristics	Age groups							
	40-49		50-59		60-69		70+	
	Percent	Mortality	Percent	Mortality	Percent	Mortality	Percent	Mortality
Gender								
Male	54.2	1.2	54.1	2.3	50.8	3.8	41.3	8.3
Female	45.8	0.7	45.9	1.8	49.2	3.2	58.7	6.7
Ambulation								
High: walks well alone at least 6.10m, balances well	79.4	0.7	77.1	1.5	70.3	2.9	56.3	5.2
Intermediate	11.4	1.7	13.3	2.9	18	5.3	29.8	10.2
Low: does not walk	9.2	2.3	9.6	5.6	11.7	4.3	13.9	10.1
Hand use								
High: uses fingers independently of each other	83.6	0.8	84.5	1.6	83.9	3.4	83.4	7.4
Intermediate: raking motion or grasps/uses thumb and fingers in opposition	14.5	1.6	13.9	4.6	14.5	3.1	15.3	7.2
Low: no functional use of hand	1.9	2.1	1.6	6	1.6	12.9	1.3	7.7
Rolling and sitting								
High: assumes and maintains sitting position independently	91.2	0.8	91.1	1.7	90.4	3.2	87.4	6.7
Intermediate	7.3	1.9	7.5	5.5	8.2	5.6	11.6	13
Low: does not lift head when lying	1.5	4.8	1.4	10.7	1.4	11.1	1	0
Toileting								
High: goes to toilet by self, completes by self	68	0.7	68.1	1.3	64.9	2.9	51.8	4.9
Intermediate	23.6	1.3	24.3	3	26.9	4.5	36.7	9.6
Low: not toilet trained or habit trained	8.4	2	7.6	6.8	8.2	4.9	11.5	11.4

Table B3

Person-Years (n=17,140) Classified by Residence Type and Subject Characteristics

Characteristic	Placement							
	Own home		Community care		Health Facility		Institution	
	%	Mortality	%	Mortality	%	Mortality	%	Mortality
Gender								
Male	52	1	54.1	1.7	47	5.4	59	2.9
Female	48	1.2	45.9	1.4	53	3.8	41	1.4
Ambulation								
High: walks well alone at least 6.10 m, balances well	88.4	0.9	85.9	1.5	39.9	3.7	53.1	0.7
Intermediate	8.3	2.4	12.1	2	29.6	6.6	16.2	3.5
Low: does not walk	3.2	4.1	2	2.2	30.4	3.8	30.8	4.4
Hand use								
High: uses fingers independently of each other	93	1	90.9	1.4	65.2	5.1	56.2	1.8
Intermediate: raking motion or grasps/uses thumb and fingers in opposition	6.4	1.6	8.8	2.7	31	3.9	36.1	2.5
Low: no functional use of hand	0.6	7.9	0.2	0	3.8	1.1	7.7	5.5
Rolling and sitting								
High: assumes and maintains sitting position independently	96.8	1	97.7	1.5	73.4	4.6	71.9	1.2
Intermediate	2.8	4.7	2.2	2.7	24.6	4.4	20.4	4.1
Low: does not lift head when lying on stomach	0.3	5	0.1	11.1	2	4.3	7.7	7.3
Toileting								
High: goes to toilet by self, completes by self	89.2	0.9	75.5	1.3	29.2	4.7	16.8	0.6
Intermediate	9.3	2.5	22.8	2.3	50.6	4.7	47.4	1.6
Low: not toilet trained or habit trained	1.5	4.5	1.7	4.3	20.2	4.1	35.9	4.1

Table B4

Logistic Regression Model Predicting Annual Mortality Probability

Variable	Odds ratio	95% confidence interval for odds ratio
		(lower, upper)
Age Male	1.048	(1.023, 1.074)
Age Female	1.055	(1.029, 1.082)
Female4	0.46	(0.16, 1.34)
Self14	6.15	(0.63, 60.13)
Self24	4.02	(0.62, 26.08)
Self34	0.73	(0.17, 3.17)
Age Self1	0.997	(0.959, 1.036)
Age Self2	0.995	(0.964, 1.027)
Age Self3	1.016	(0.990, 1.043)
Tube4	1.49	(0.68, 3.24)
Motor14	0.88	(0.27, 2.88)
Motor24	1.01	(0.59, 1.74)
Motor34	1.31	(0.99, 1.73)
Home4	1.13	(0.81, 1.57)
Health4	1.78	(1.31, 2.43)
Institutions4	0.9	(0.61, 1.34)

Table B5  
Percentages of Person-Years and Mortality Rates for Some Client Evaluation Report  
Variables (n=? Person-Years)

Replication of Strauss et al, (1994), American Journal of Public Health, 86 (10): 1422-1429)

	Person-Years, %	Mortality Rate, %
All (n=3116)	100	4.1
Rolling and sitting		
Does not lift head when lying on stomach	24.4	7.4
Lifts head when lying on stomach	21.5	4.8
Lifts head and chest using arm support when lying on stomach	7.1	3.2
Rolls from side to side	9.3	4.1
Rolls from front to back only	6.4	0.5
Rolls from front to back and back to front	15.6	2.5
Maintains sitting position with minima support for at least 5 minutes	8.3	1.5
Sits without support for at least 5 minutes	3.6	0.9
Assumes and maintains sitting position independently	3.9	1.7
Hand use		
No functional use of hands	38.2	5.3
Has use of hands	61.8	3.3
Crawling		
Does not creep, crawl, or scoot	82.3	4.3
Creeps, crawls, or scoots without the ability to stand	17.7	3.1
Tube feeding		
No feeding tube	70.3	3.1
Has feeding tube	29.7	6.5
Placement (Health facility includes SNF)		
Own home	78.3	3.9
Community care	8.5	4.2
Health facility	7.8	4.1
Developmental center	5.4	6.6
Placement (SNF separate)		
Own home	78.3	3.9
Community care	8.5	4.2
Health facility	7.2	4.0
SNF	0.6	5.0
Developmental center	5.4	6.6
Interaction with persons other than peers		
No interaction	55.6	5.1
Some interaction	44.4	2.8
Auditory Perception		
Does not react, demonstrate startle, or turns head or eyes to sound sources	46.5	4.9
Responds differently to voices	53.5	3.4
Receptive language		
Does not understand speech	63.4	4.6
Some understanding	36.6	3.2
Mental Retardation		
Mild	4.7	3.8
Moderate	7.4	1.9
Severe	23.5	3.5
Profound	39.4	4.6
Not/suspected	25.0	4.8
Age, y		
2	13.5	3.1
3	12.3	3.7
4	10.4	4.0
5	9.6	4.0
6	9.3	3.4
7	6.9	4.2
8	6.9	7.5
9	5.4	4.1
10	5.9	2.7
11	5.4	4.1
12	5.0	5.1
13	5.1	5.7
14	4.4	2.9

Table B6

Logistic Regression Model for Mortality Based in 3,116 Person-Years

Variable	Odds ratio	95% Confidence interval	P-value
TF & MOBIL1	6.70	3.08, 14.60	0.0000
TF & MOBIL2, 3, 4	3.55	1.77, 7.11	0.0004
Not TF & MOBIL1	4.48	2.03, 9.85	0.0002
Not TF & MOBIL2	3.25	1.55, 6.80	0.0017
Not TF & MOBIL3	1.20	0.52, 2.80	0.6686
Hand use	0.87	0.56, 1.34	0.5154
Crawling	0.75	0.42, 1.34	0.3270
Interaction with non-peers	1.56	0.99, 2.44	0.0533
Auditory perception	0.94	0.61, 1.44	0.7608
Receptive language	0.96	0.60, 1.52	0.8510
Community care	0.92	0.48, 1.75	0.7893
Health facility (with SNF)	0.78	0.32, 1.89	0.5817
Institution	0.77	0.31, 1.93	0.5770

Table B7

Logistic Regression Model for Mortality Based in 3,116 Person-Years with Skilled  
Nursing Facility (SNF) Separate

Variable	Odds ratio	95% Confidence interval	P-value
TF & MOBIL1	6.70	3.07, 14.59	0.0000
TF & MOBIL2, 3, 4	3.55	1.77, 7.11	0.0004
Not TF & MOBIL1	4.48	2.03, 9.86	0.0002
Not TF & MOBIL2	3.25	1.55, 6.81	0.0017
Not TF & MOBIL3	1.20	0.52, 2.80	0.6680
Hand use	0.87	0.56, 1.34	0.5153
Crawling	0.75	0.42, 1.34	0.3266
Interaction with non-peers	1.56	0.99, 2.44	0.0532
Auditory perception	0.94	0.61, 1.44	0.7611
Receptive language	0.96	0.60, 1.52	0.8489
Community care	0.92	0.48, 1.75	0.7892
Health facility	0.77	0.31, 1.92	0.5795
SNF	0.84	0.10, 7.06	0.8760
Institution	0.77	0.31, 1.93	0.5782



Subject Code / Client ID: «Client»

**EXPERT PANEL CODING FORM****Note:** If this case should be reviewed by a different physician/nurse, please specify type: \_\_\_\_\_**CAUSE OF DEATH - Only Physicians Answer 1-2****1. Based on available data, what was the immediate cause of death?**

Immediate cause \_\_\_\_\_

**2. Based on available data, were there any antecedent causes of death?**

Death due to / associated with \_\_\_\_\_

Death due to / associated with \_\_\_\_\_

Death due to / associated with \_\_\_\_\_

**What was the underlying cause of death?** \_\_\_\_\_**Related significant condition:****Comments:****SPECIAL CARE DIRECTIVES - Physicians and Nurses Answer 3 -16****3. a. Were Special Care Directives (for example, DNR) noted in the report?**

Yes\_\_\_\_ No\_\_\_\_

**Comments:**

Subject Code / Client ID: «Client»

**b. Given the health status of the individual, were the Special Care Directives appropriate?**

Yes \_\_\_\_\_ No \_\_\_\_\_ Insufficient Documentation \_\_\_\_\_

**Comments:**

**c. Were directives followed?**

Yes \_\_\_\_\_ No \_\_\_\_\_ Insufficient Documentation \_\_\_\_\_

**Comments:**

**EMERGENCY RESPONSE**

**4. a. Was emergency care/response needed?**

Yes \_\_\_\_\_ No \_\_\_\_\_ Insufficient Documentation \_\_\_\_\_

**Comments:**

**b. Did residential staff provide appropriate care?**

Yes \_\_\_\_\_ No \_\_\_\_\_ Insufficient Documentation \_\_\_\_\_

**Comments:**

**c. Was care by Paramedics/Emergency response team appropriate?**

Yes \_\_\_\_\_ No \_\_\_\_\_ Insufficient Documentation \_\_\_\_\_ N/A \_\_\_\_\_

**Comments:**

**d. Was care in Emergency Room appropriate?**

Yes\_\_\_\_ No\_\_\_\_ Insufficient Documentation\_\_\_\_ N/A\_\_\_\_

Comments:

**SERVICES PROVIDED BY PHYSICIANS**

**5. a. Did preventive care meet the usual standard of practice for age, gender and functioning level?**

Yes\_\_\_\_ No\_\_\_\_ Insufficient Documentation\_\_\_\_

Comments:

**b. If not, did lack of preventive care contribute to the death?**

Yes\_\_\_\_ No\_\_\_\_ Insufficient Documentation\_\_\_\_

Please specify needed preventive care.

**6. a. Was ongoing medical management by MD appropriate?**

Yes\_\_\_\_ No\_\_\_\_ Insufficient Documentation\_\_\_\_

Comments:

**b. If no, which of the following could have contributed to the death?**

- \_\_\_\_ Medication mismanagement, specify: \_\_\_\_\_
- \_\_\_\_ Delayed diagnosis, specify: \_\_\_\_\_
- \_\_\_\_ Missed diagnosis, specify: \_\_\_\_\_
- \_\_\_\_ Inadequate lab screening, specify: \_\_\_\_\_
- \_\_\_\_ Delayed referral to subspecialist, specify: \_\_\_\_\_
- \_\_\_\_ Lack of referral to subspecialist, specify: \_\_\_\_\_
- \_\_\_\_ Health plan/insurance restrictions, specify: \_\_\_\_\_
- \_\_\_\_ Referral restrictions by plan, specify: \_\_\_\_\_
- \_\_\_\_ Insurance coverage, specify: \_\_\_\_\_
- \_\_\_\_ Type of provider, specify: \_\_\_\_\_

\_\_\_ If multiple providers, specify which was problematic: \_\_\_\_\_  
\_\_\_ Delayed MD follow-up, specify: \_\_\_\_\_  
\_\_\_ No MD follow-up, specify: \_\_\_\_\_

**Comments:**

**CONSUMER**

7. a. Did consumer's refusal to cooperate with health care or treatment recommendations contribute to the death?

Yes\_\_\_ No\_\_\_ Insufficient Documentation\_\_\_

**Comments:**

7. b. Did the consumer's lifestyle choices contribute to the death?

Yes\_\_\_ No\_\_\_ Insufficient Documentation\_\_\_

**Comments:**

8. a. Did the consumer's condition contribute to the death?

Yes\_\_\_ No\_\_\_ Insufficient Documentation\_\_\_

**Comments:**

- 8 b. Did the consumer's actions contribute to the death?

Yes\_\_\_ No\_\_\_ Insufficient Documentation\_\_\_

**Comments:**

**8. c. Did criminal activity by the consumer contribute to the death?**

Yes\_\_\_\_ No\_\_\_\_ Insufficient Documentation\_\_\_\_

**Comments:**

**9. Did the family or guardian's choice regarding the medical management follow-up, hospitalization, or treatment contribute to the consumer's death?**

Yes\_\_\_\_ No\_\_\_\_ Insufficient Documentation\_\_\_\_

**Comments:**

**SERVICES PROVIDED BY RESIDENTIAL SERVICE PROVIDER**

**10. Was the level(s) of care of the primary residence appropriate for the consumer's medical/nursing needs and conditions?**

Yes\_\_\_\_ No\_\_\_\_ Insufficient Documentation\_\_\_\_

**Comments:**

**11. If the consumer's medical/nursing needs and conditions changed, was the consumer transferred to the appropriate level of care?**

Yes\_\_\_\_ No\_\_\_\_ Insufficient Documentation\_\_\_\_

**Comments:**

**12. Were there health care plans for the day-to-day management of the consumer's needs?**

Yes \_\_\_\_\_ No \_\_\_\_\_ Insufficient Documentation \_\_\_\_\_

**Comments:**

**13. If yes, how would you rate the adequacy of the care plans for meeting the consumer's needs?**

☐ Inadequate  
☐ Minimally adequate  
☐ Adequate  
☐ Very good  
☐ Excellent

**Comments:**

**14. a. Was the ongoing health care provided in the consumer's place of residence appropriate?**

Yes \_\_\_\_\_ No \_\_\_\_\_ Insufficient Documentation \_\_\_\_\_

**b. If not, which of the following could have contributed to the death?**

☐ Not following plan of health care  
☐ Not providing appropriate treatments  
☐ Missed doctor appointments  
☐ Did not give medications as prescribed  
☐ Did not know when to get professional help  
☐ Did not protect consumer from dangerous behaviors (i.e. fire setting, uncontrolled eating, etc.)  
☐ Did not increase supervision when behavior changed and warranted it  
☐ When inconvenient, did not provide care for consumer  
☐ Did not respond to adverse medication reactions  
☐ Did not recognize acute illness or health status deterioration  
☐ Lack of medical management, specify.  
☐ Lack of nursing management, specify.  
☐ Use of restraints  
☐ Use of other restrictive procedures  
☐ Medical equipment malfunction  
☐ Safety equipment not working

**Comments:**

**15. a. Could better residential care have prevented death?**

Yes\_\_\_\_ No\_\_\_\_ Insufficient Documentation\_\_\_\_

**Comments:**

**15. b. If yes, what care do you feel should have been provided?**

**HEALTH CARE SYSTEMS**

**16. Could improvements in the health care delivery system have possibly prevented the death of this consumer?**

**SECONDARY CODING FORM**

Client ID # \_\_\_\_\_  
 Coder Initials \_\_\_\_\_

Expert ID # \_\_\_\_\_  
 Date \_\_\_\_\_

**A. Overall Documentation**

- ☐ Adequate  
☐ Inadequate  
     ☐ Too little information to judge  
     ☐ Information but with gaps

B.	Question miscoded	Correct Code

**6b. If no, which of the following could have contributed to death?**

\_\_\_ Medication mismanagement, specify \_\_\_\_\_

- |   |    |   |
|---|----|---|
| ___ Delayed diagnosis/ Missed diagnosis                   | or | ___ Delayed or no MD follow-up                        |
| <input type="checkbox"/> dysphagia                        |    | <input type="checkbox"/> social/emotional/ behavioral |
| <input type="checkbox"/> constipation/impaction           |    | <input type="checkbox"/> seizures                     |
| <input type="checkbox"/> other GI problems                |    | <input type="checkbox"/> diabetes/other endocrinology |
| <input type="checkbox"/> GERD                             |    | <input type="checkbox"/> cardiac                      |
| <input type="checkbox"/> aspiration/ recurrent aspiration |    | <input type="checkbox"/> fractures/injury             |
| <input type="checkbox"/> respiratory general              |    | <input type="checkbox"/> adverse medication reaction  |
| <input type="checkbox"/> urinary/renal problems           |    | <input type="checkbox"/> weight change                |
| <input type="checkbox"/> fluid management                 |    | <input type="checkbox"/> inadequate lab or x-ray      |
| <input type="checkbox"/> decubiti/other skin disorder     |    | <input type="checkbox"/> care not aggressive enough   |

\_\_\_ Delayed or lack of referral to subspecialist, specify

- |  |  |
|--|--|
| <input type="checkbox"/> clinical nurse specialist | <input type="checkbox"/> orthopedics             |
| <input type="checkbox"/> cardiology                | <input type="checkbox"/> pharmacology            |
| <input type="checkbox"/> dental                    | <input type="checkbox"/> Physical therapy        |
| <input type="checkbox"/> dermatology               | <input type="checkbox"/> Gastroenterology        |
| <input type="checkbox"/> endocrinology             | <input type="checkbox"/> psychiatry / psychology |
| <input type="checkbox"/> neurology                 | <input type="checkbox"/> pulmonology             |
| <input type="checkbox"/> Nutritionist              | <input type="checkbox"/> Speech / audiology      |
| <input type="checkbox"/> occupational therapy      | <input type="checkbox"/> Other specify _____     |

\_\_\_ Health plan/insurance restrictions, specify \_\_\_\_\_



**Residential Care Provider**

**14b. Did not respond to needs of client:**

☐ Safety

☐ Health

- |  |  |
|--|--|
| <input type="checkbox"/> dysphagia                       | <input type="checkbox"/> diabetes/other endocrinology                          |
| <input type="checkbox"/> Constipation/impaction          | <input type="checkbox"/> cardiac   |
| <input type="checkbox"/> other GI problems               | <input type="checkbox"/> fractures/injury                                      |
| <input type="checkbox"/> GERD                            | <input type="checkbox"/> known allergy/gave med                                |
| <input type="checkbox"/> Aspiration/recurrent aspiration | <input type="checkbox"/> nutrition   |
| <input type="checkbox"/> Respiratory general             | <input type="checkbox"/> delayed contact of M.D.                               |
| <input type="checkbox"/> urinary/renal problems          | <input type="checkbox"/> no/limited supportive care                            |
| <input type="checkbox"/> fluid management                | <input type="checkbox"/> delayed referral to higher level of care              |
| <input type="checkbox"/> decubiti/other skin disorder    | <input type="checkbox"/> did not recognize/respond to changes in health status |
| <input type="checkbox"/> seizures                        |  |

☐ Social / emotional / behavioral

**16. Could improvements in the health care delivery system have possibly prevented the death of this consumer?**

☐ Yes

☐ System

☐ Medical

☐ Residential

☐ No

## Secondary Coding Protocol

Many expert panelists consistently wrote comments on their forms, two research nurses reviewed all comments with the goal of developing a coding system that would capture this data in a meaningful manner. The nurses each separately reviewed 40 Expert Panelist forms, keeping notes on their observations. The two research nurses met, and reviewed their findings. In some instances, expert panelist's comments were not consistent with their checked choices, indicating that the wrong box had been checked. Comments generally contained valuable information regarding the expert's view of the care of the individual who had died. A comprehensive coding system was developed that would ensure that data were captured. Forty Expert Panelist forms records were each reviewed and coded by 2 nurses, who then met and compared finding. Most of the time substantive comments fell within a narrow range and concerned an aspect of medical or residential care. A more concise system was then developed that included the following:

- Correction of miscoded (based on comments) checks,
- Evaluation of the adequacy of documentation
- Identification of deficits in medical care
- Identification of barriers to specialty care services
- Identification of deficits in residential care
- An overall assessment of whether better care could have prevented the death

The following criteria were followed for each of these areas of review:

**Correction of miscoded checks:** Comments for each question checked were compared to the box checked on the Expert Panel Coding Form. When the comments were inconsistent with the box checked, a note was made, and the need for correction was noted.

**Evaluation of the adequacy of documentation:** There were two possible options for coding a record as "inadequate."

- a. Inadequate- too little to judge
  - Medical care (6a): documentation inadequate to judge care
  - Residential care (14a): ): documentation inadequate to judge care
- b. Inadequate-information but with gaps

*Scenario 1:*

- Medicare (6a): care judged
- Residential care (14a): ): documentation inadequate to judge care

*Scenario 2:*

- Medical care (6a): documentation inadequate to judge care
- Residential care (14a): Care judged.

**Identification deficits in medical care:** Medical care deficits were noted to e due to misses diagnosis, or delayed diagnosis. The type of problem was coded, for example cardiac, cancer, inadequate follow-up lab or x-ray.

**Identification of barriers to specialty care services:** Barriers to specialty services were noted, as was the type of specialist, such as neurologist, pulmonologist, physical therapy.

**Identification of deficits in residential care:** Deficits in residential care were coded within 3 categories: safety, health, or emotional/behavioral. Safety was noted to be related to supervision or else specified. Health was categorized by the type of problem, i.e. decubiti, and the type of service, such as failure to contact the physician in a timely manner. Emotional/behavioral was specified.

**An overall assessment of whether better care could have prevented the death:** Comments were coded as “yes” or “no”, and , when specified, “yes” comments were noted as being related to medical and/or residential care, based on he written comments.

**PHYSICIAN EXPERTS**

<b>NAME</b>	<b>AFFILIATION</b>	<b>LOCATION</b>
Dr. Kimberly Bedell	Private Practice	Northridge, CA
Dr. Saral Gnanamuthu	Private Practice	West Lake, CA
Dr. Allen Crocker	Boston Children's Hospital	Boston, MA
Dr. Herbert Grossman	University of Michigan, Women's Hospital	Ann Arbor, MI
Dr. Robert Allport	Retired	Portland, OR
Dr. Chahira Kozma	Georgetown University Medical Center	Washington, DC
Dr. Angelo Giardino	Philadelphia Children's Hospital	Moorestown, NJ
Dr. Marianne Mereugliano Glanz	Philadelphia Children's Hospital	Philadelphia, PA
Dr. Sandra Friedman	Boston Children's Hospital	Boston, MA
Dr. Patrick S. Romano	UC Davis Medical Center	Sacramento, CA

**NURSE EXPERTS**

<b>NAME</b>	<b>AFFILIATION</b>	<b>LOCATION</b>
Linda Ross	Westchester Institute for Human Development	Valhalla, NY
Addria Hodas, RN, MSN	Toward Independent Living & Learning	Deham, MA
Lee Barks, RN, MN	Development Health Inc.	Longwood, FL
Joyce Pulcini	Hunter College	New York, NY
Stephen Wallace, RN	Developmental Disabilities Nursing Association	Riverside, CA
Lorene Reagan, RN	Department of Health and Human Services	Nottingham, NH
Eunice Shishmanian, RN	Northeastern University	Waban, MA
Wendy Hehring, RN, PhD	University of Miami	Miami, FL
Kathy Elliot, RN	California Department of Health & Human Services	Dixon, CA
Jean M. Sherman, Ed.D., RN	University of Miami, Center on Aging & Development	Miami, FL
Marissa C. Brown MSN, RN	Georgetown University Medical Center	Washington, DC

Tables E1 and E2 show the results for ratings of individual items by setting. Table E1 compares all settings, and Table E2 compares subdivisions of Developmental Centers to their community counterpart.

<b>Table E1.</b> <b>Mann-Whitney Test P-Values for Comparing Quality Ratings by Placement for Individual Items</b>										
<b>Variables</b>	P-value	P-value	P-value	P-value	P-value	P-value	P-value	P-value	P-value	P-value
	DC vs. SNF	DC vs. CCF	DC vs. ICF	DC vs. Other	SNF vs. CCF	SNF vs. ICF	SNF vs. Other	CCF vs. ICF	CCF vs. Other	ICF vs. Other
Residence adequate	0.00	0.00	0.00	0.13	0.81	0.81	0.31	0.65	0.19	0.37
Care plan in place	0.00	0.00	0.00	0.00	0.00	0.90	0.16	0.00	0.98	0.20
Care plan rating	0.00	0.00	0.00	0.01	0.06	1.00	0.71	0.16	1.00	0.77
Delayed/missed diagnosis	0.00	0.00	0.00	0.78	0.40	0.76	0.19	0.72	0.11	0.15
Delayed subspecialist referral	0.00	0.00	0.01	1.00	0.84	0.67	0.41	0.87	0.57	0.57
ER care appropriate	0.63	0.29	1.00	1.00	0.11	1.00	1.00	0.39	1.00	1.00
Health plan restrictions	0.14	0.29	1.00	1.00	1.00	0.54	1.00	1.00	1.00	1.00
Improvement of system could have prevented death	0.00	0.00	0.00	0.98	0.02	0.06	0.25	0.95	0.02	0.02
Medical improvements could have prevented death	0.02	0.01	0.00	1.00	0.64	0.20	0.58	0.42	0.56	0.26
Residential care improvements could have prevented death	0.00	0.00	0.01	1.00	0.17	0.96	0.21	0.40	0.07	0.26
Level of care adequate	0.00	0.00	0.00	0.00	0.01	0.41	0.32	0.22	1.00	0.73
Transfer to Appropriate Level of care	0.13	0.02	0.09	0.18	0.45	0.70	0.53	0.84	1.00	0.74
Medication mismanagement	0.36	0.90	0.60	1.00	0.31	0.80	1.00	0.58	1.00	1.00
Ongoing medical management adequate	0.00	0.00	0.00	1.00	0.67	0.83	0.09	0.88	0.05	0.05
Paramedic response appropriate	0.61	0.66	0.01	0.57	0.41	0.01	0.55	0.05	0.60	1.00
Preventive care met standards	0.00	0.00	0.00	0.03	0.06	0.91	0.70	0.18	0.27	0.74
Lack of preventive care contributed to death	0.00	0.00	0.00	1.00	0.05	0.71	1.00	0.20	0.50	1.00
Staff ER care appropriate	0.01	0.01	0.65	0.29	0.74	0.09	0.98	0.14	0.96	0.32
Better care needed	0.00	0.00	0.00	1.00	0.04	0.20	0.19	0.74	0.01	0.05
Residential care, safety issue	0.09	0.00	0.14	1.00	0.06	1.00	0.64	0.10	0.32	1.00
Residential care, health issue	0.00	0.00	0.00	0.06	0.89	0.41	0.60	0.35	0.60	0.41
Social/behavioral/emotional needs not met by residential care provider	1.00	0.26	1.00	1.00	0.38	1.00	1.00	1.00	1.00	1.00

<b>Table E2</b> <b><u>Mann-Whitney Test P-Values for Comparing Quality Ratings by</u></b> <b><u>Sub-Division of Developmental Center Placement for Individual</u></b> <b><u>Items</u></b>		
<b>Variables</b>	DC-SNF vs. SNF	DC-ICF vs. ICF
Residence adequate	0.00	0.00
Care plan in place	0.00	0.00
Care plan rating	0.00	0.00
Delayed/missed diagnosis	0.00	0.05
Delayed subspecialist referral	0.00	0.63
ER care appropriate	0.59	1.00
Health plan restrictions	0.20	1.00
Improvement of system could have prevented death	0.01	0.00
Medical improvements could have prevented death	0.11	0.08
Residential care improvements could have prevented death	0.01	0.07
Level of care adequate	0.00	0.01
Transfer to appropriate level of care	0.16	0.36
Medication mismanagement	0.37	1.00
Ongoing medical management adequate	0.00	0.00
Paramedic response appropriate	0.78	0.29
Preventive care met standards	0.00	0.00
Lack of preventive care contributed to death	0.01	0.05
Staff ER care appropriate	0.01	0.34
Better care needed	0.00	0.00
Residential care, safety issue	0.22	0.52
Residential care, health issue	0.00	0.01
Social/behavioral/emotional needs not met by residential care provider	1.00	1.00

**Table F**  
**Death Rates for Individuals with Developmental Disabilities Compared to the General Population**

Age group	Females % Genl popn	Females, % DDS popn	Females genl death rate (%)	Females, DDS death rate (%)	Males % genl popn	Males % DDS popn	Males, genl death rate (%)	Males, DDS death rate (%)
1-5	4.5	4.1	0.03	1.39	4.7	5.9	0.04	0.89
6-12	5.1	6.5	0.01	0.73	5.3	9.9	0.02	0.70
13-17	3.2	3.9	0.03	0.37	3.4	5.4	0.08	0.85
18-21	2.5	3.4	0.05	0.72	2.8	4.2	0.17	0.71
22-29	6.1	7.7	0.05	0.56	7.0	9.6	0.16	0.59
30-39	8.9	8.8	0.09	0.79	9.4	11.0	0.26	0.71
40-44	3.8	3.2	0.16	0.57	3.8	3.8	0.39	1.15
45-49	3.2	2.1	0.23	1.32	3.2	2.6	0.48	1.33
50-54	2.4	1.3	0.39	1.05	2.4	1.6	0.66	1.91
55-59	2.0	0.9	0.59	2.26	1.9	1.0	0.95	3.12
60-64	1.8	0.6	0.94	3.41	1.7	0.6	1.53	3.84
65-69	1.8	0.5	1.48	2.52	1.5	0.5	2.30	5.03
70+	4.5	0.6	5.32	6.66	3.0	0.5	6.52	7.92

\*Population served by DDS includes only those with active status code (1,2, or 8) as of 12/31/93, known vital status and apparently active through 1994 (or until death), and with a CDER since 12/31/90.

For general population, total n=31,217,221;deaths = 218,820.

For DDS population, total n = 103,918; deaths = 1,001.